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

3

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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: Sixteen 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 comorbidities 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

1 typologies and facets of pacing warrant further investigation to facilitate the
2 development of effective tailored pacing interventions.

3

4 **Keywords (max 6):** Activity pacing

5 Questionnaire

6 Acceptability

7 Qualitative

8 Chronic pain

9 Chronic fatigue

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 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

1 cycling, symptom-contingency/energy conservation and graded activity, without a clear
2 consensus on one description [4,11,21].

3
4 Despite the proposed benefits of pacing, the empirical evidence is sparse and
5 conflicting; pacing being associated with better and worsened symptoms [1,6]. This
6 may be partly due to the absence of a widely accepted pacing scale. There are pacing
7 subscales within the Coping with Rheumatic Stressors questionnaire (CORS) [22], the
8 Chronic Pain Coping Inventory (CPCI) [9], the Pain and Activity Relations
9 Questionnaire (PARQ) [5] and the Patterns of Activity Measure-Pain (POAM-P) [7].
10 However, existing pacing subscales appear limited in content, reflecting concepts of
11 reducing over-exertion, but not reducing under-exertion/fluctuating activities.
12 Furthermore, there is no validated scale for patients whose predominant symptom is
13 fatigue. To date, the acceptability of existing subscales has not been explored.
14 Acceptability has been defined as “the degree to which somebody agrees that
15 something is good enough to use or allow” [23]. Therefore the content of existing
16 scales may not reflect patients’ interpretations of pacing.

17
18 We have developed an Activity Pacing Questionnaire using mixed methods (see Figure
19 1). Stage I, the Delphi technique, involved 49 clinicians and 10 patients to develop the
20 original 38 questionnaire items [24]. Stage II, the psychometric study, implemented a
21 cross-sectional, questionnaire design study. Following factor analysis, 12 items were
22 removed and five broad themes of pacing emerged in the APQ-26. Each theme
23 demonstrated satisfactory internal consistency (Cronbach’s $\alpha=0.72-0.92$), test-retest
24 reliability (intraclass correlation coefficient, ICC=0.50-0.78, $p\leq 0.001$) and construct

1 validity against the CPCI and PARQ pacing subscales [25]. This paper presents Stage
2 III, the acceptability component. The aims of Stage III were twofold:
3 1.) explore patients' views and beliefs about the concept of pacing
4 2.) assess the acceptability of the APQ-38, and CPCI and PARQ pacing
5 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 Figure 2*).

APQ and comparator pacing subscales¹

The APQ [24] contained 38 items involving facets such as splitting up tasks, setting goals and gradually increasing activities. Items are rated on a 5-point Likert scale (0='never did this', 1='rarely did this', 2='occasionally did this', 3='frequently did this' and 4='always did this'). Items refer to physical, cognitive and social activities, and are rated over the past seven days. Participants discussed the original APQ-38 that they completed in Stage II, the psychometric study.

The CPCI pacing subscale [9] contains six items measuring going 'slow and steady', breaking down tasks and using breaks. The CPCI pacing subscale is rated as a number of days (0-7). The PARQ pacing subscale [5] contains six items referring to doing tasks more slowly, stopping/splitting activities and using rests. The PARQ is rated on a 6-point Likert scale with the labels: 0='never' and 5='always'. The PARQ does not instruct a recall period. The CPCI and PARQ pacing subscales previously demonstrated high internal consistency (Cronbach's $\alpha=0.95$; Cronbach's $\alpha=0.89$ respectively); and fair-to-good test-retest reliability (CPCI pacing subscale ICC=0.47, 95% CI 0.24-0.65, $p<0.001$; PARQ pacing subscale ICC=0.68, 95% CI 0.52-0.79, $p<0.001$) [25].

¹ The pacing subscales of the CORS and POAM-P were omitted from the study since the CORS has not been validated in English and was developed specifically for rheumatoid arthritis, and the POAM-P was published after this study was undertaken.

1

2 *Participants*

3 Participants were recruited via purposive sampling, involving those who had completed
4 the psychometric study within the previous year (see Figure 1). Participants had been
5 referred to physiotherapy out-patients departments in a North West England NHS Trust
6 with primary diagnoses of chronic low back pain, chronic widespread
7 pain/fibromyalgia and/or CFS/ME (all ≥ 3 months' duration), and were aged ≥ 18 years.
8 Patients with a serious underlying pathology, inflammatory condition, or neurological
9 condition were excluded. Patients were required to have a good understanding of
10 English as it was unfeasible to translate the questionnaires/interviews due to limited
11 resources.

12

13 Patients were invited to participate over the telephone and received postal study
14 information, including an uncompleted APQ-38 to act as an aide-memoire for the
15 interviews. Participants gave written consent to the postal information and verbal
16 consent at the beginning of the interview recording. A pilot interview helped gauge the
17 interview duration and the suitability of the questions. Following the pilot, no major
18 changes were required. Therefore, this interview was included in the analysis.

19

20 *Data collection*

21 Interviews were digitally recorded and transcribed *verbatim* (by DA) for continuous
22 data analysis and interview development. Fieldnotes documented contextual
23 issues/prompts for data analysis [26,27]. Participants' anonymity was maintained using
24 a coding system. Participants were invited to read, amend if necessary and sign their
25 interview transcription.

1

2 *Data analysis*

3 Data were analysed using Framework analysis: a five-step, iterative matrix method
4 [28-31]. Framework analysis allows both deductive processes (analysis of original
5 research aims/themes) and inductive processes (emergence of new themes); therefore
6 apposite for analysing data from semi-structured interviews [29,31]. The analysis was
7 undertaken by DA in discussion with the co-authors (LM, PK, MC, SW). Data analysis
8 commenced during interview transcription to facilitate the detection of data saturation
9 when no new concepts emerged [26,32]. The qualitative data were managed using the
10 NVivo9 program.

11

Findings

Forty-one patients agreed to receive the study information, of whom sixteen consented to participate (response rate=39%). Participants' demographic data are summarised in Table 1. Framework analysis found three main themes of discussion deductively (arising from specific interview questions): the concept of pacing; co-morbidities/emotions influencing pacing; and pacing scale acceptability. Different behavioural typologies emerged inductively during data analysis.

Concept of pacing

Participants interpreted 'activity pacing' as involving varying facets. Pacing was described as a strategy to adjust activities to prevent exacerbating symptoms:

“Managing your day to day activities, spreading them evenly if you possibly can to reduce some of your symptoms.” (RN318)

Pacing was described as managing activities by: “taking a break”, “have a rest”, “do it slowly”, together with limiting the amount of activity, alternating activities/positions and possibly avoiding activities (for example, exercises/social events). Such facets were reported to be both encouraged and discouraged by others (family members/friends/physiotherapists). Participants did not always feel in control of adapting their activities and barriers included work-related pressures.

Participants reported that pacing may involve assessing their activities and setting realistic goals. Participants tried to plan the practicalities, prioritisation and duration

1 of activities. Activities were planned across days, and strenuous activities were
2 coincided with lighter tasks/pleasurable activities:

3

4 *“...if I’m doing an activity in the day, like some sort of exercise routine, I*
5 *make sure maybe that the next day I won’t do anything to give me time to*
6 *recover.” (PW048)*

7

8 Barriers that prevented planning activities included fulfilling caring roles, duties at
9 work and the condition itself:

10

11 *“I do have a little routine...maybe it will get thrown out because I’m*
12 *working...” (PW048)*

13

14 *“I could think about planning, but because I have ME, it doesn’t matter*
15 *how much I plan, I never know how I’m going to feel or what my abilities*
16 *are going to be on that particular day.” (PB133)*

17

18 Participants described pacing as trying to maintain consistent levels of activities rather
19 than fluctuating patterns to achieve *“more good days”*. This involved not over-doing
20 activities on ‘good’ days, whilst engaging in modified activities on ‘bad’ days.

21

22 Three participants (aged 24-35 years) believed that pacing involved gradually
23 increasing activities over time (such as household tasks/exercise):

24

1 *“...one of the physiotherapists who suggested to maybe just do a little bit*
2 *each day...I do little chunks at a time, and then build up when I felt I could*
3 *do a bit more.” (PG017)*

4

5 Three participants (aged >60 years) reported being unable to gradually increase their
6 activities; the barriers for which included increasing age and worsening symptoms.

7

8 Some participants described pacing as being assertive, asking for help and saying
9 ‘no’. Other facets included accepting activity capabilities, reducing self-imposed
10 pressure to complete tasks (perfectionist tendencies) and changing activity targets if
11 unrealistic:

12

13 *“It is a ‘no’ to myself...but quite often ‘no’ to other people. You kind of*
14 *learn what brings your symptoms on, what aggravates them, and some*
15 *days you’ve just got to accept that you can’t do certain things.” (RN318)*

16

17 *“..for somebody like me who is constantly in pain and for whom there isn’t*
18 *a miracle cure, to actually cope with my life from day to day, I have to*
19 *mentally make sure that I don’t try to achieve everything in one day.”*
20 *(PF011)*

21

22 Most of the facets of pacing that participants suggested are similar to the APQ items
23 (see Table 2). Facets that were suggested by participants but not included in the APQ
24 included slowing down, avoiding multi-tasking and making lists.

25

1 *Co-morbidities/emotions influencing pacing*

2 During the interviews, it emerged that the presence of co-morbidities (including short-
3 term and long-term conditions) and increasing age influenced the relevance and
4 implementation of different items of the APQ:

5

6 *“[APQ item 1]: “I gradually increased my activities”, well no, I rarely do*
7 *this. That’s obviously with a couple of other health problems as well at the*
8 *minute.” (PN309)*

9

10 *“I think now I’ve got older that I’m pacing things out a lot more.”*
11 *(RB108)*

12

13 Alongside physical conditions, participants reported that their approach to pacing or
14 general activity was also affected by emotions such as guilt, annoyance, resentment
15 and motivation:

16

17 *“...there’s a kind of resentment that builds, and that triggers my symptoms*
18 *as well.” (RN318)*

19

20 In particular, depression was highlighted as a challenge to activity. Mood was also
21 reported as affecting symptoms:

22

23 *“When you’re feeling low and fed up and you’ve got a lot of problems,*
24 *you’re at your worst. You feel so bad and your back is so bad, but it’s not*
25 *your back, it’s just you.” (RB119)*

26

1 *Pacing scale acceptability*

2 Participants found the APQ-38 instructions to be self-explanatory, but the 7-day recall
3 received mixed opinions. Ten participants found this period appropriate since it
4 included work and social activities. Three participants found the 7-day recall too long,
5 two of whom reported problems with mental fatigue. Conversely, three participants
6 preferred a longer recall period. Thirteen participants found the APQ 5-point Likert
7 scale (including word descriptors) acceptable. Most APQ-38 items were reported to
8 be relevant and understandable. Some specific items were not applicable to
9 individuals or generated confusion, for example, items referring to using flare-up
10 plans/activity diaries, or items containing a double negative such as “*I did not under-*
11 *do activities on a ‘bad’ day*”. Participants reported some items were repetitive and
12 that the number of APQ-38 items was burdensome.

13

14 In comparison, five participants reported that the CPCI pacing subscale was difficult
15 to complete due to the 0-7 day rating scale. Comments were made regarding the
16 repetition and relevance of CPCI pacing items, in particular, the term ‘slow and
17 steady’ (in three of six items). Difficulties were reported regarding items that referred
18 to distracting from, or reducing pain. Specifically, if pain was constant, strategies to
19 avoid pain were impossible.

20

21 The PARQ contains only the word descriptors 0=‘never’ and 5=‘always’ which made
22 the scale less acceptable for some participants. The PARQ Likert scale has six
23 intervals, and suggestions of having a middle option were made. Some difficulties
24 arose with PARQ pacing items that appeared to contain more than one facet, or

1 referred to pain (three of six items). Several participants did not feel able to control
2 their pain, whilst for others, the term ‘pain’ did not incorporate other symptoms.

3

4 When comparing the three pacing scales, the brevity of the PARQ and CPCI pacing
5 subscales was preferable to the length of the APQ-38. Several participants reported a
6 preference towards the Likert scale of the APQ-38 over the PARQ, and both were
7 generally favoured above the CPCI rating scale:

8

9 *“Some of the [APQ] questions they seem like double negatives, but the*
10 *scale seems a lot easier.” (PW048)*

11

12 *Activity behaviour typologies*

13 Activity behaviour typologies emerged inductively during data analysis, including
14 quota-contingent behaviours (activities driven by amount/time/distance) and
15 symptom-contingent behaviours (activities driven by symptoms). Additionally,
16 participants’ activity behaviours emerged as belonging to four typologies: Task
17 avoidance, Task persistence, Task fluctuation (boom-bust) and Task modification
18 (activity pacing).

19

20 Task avoidance behaviour involved stopping/avoiding activities and was often led by
21 symptom-contingency:

22

23 *“I tend to go off how I actually feel. If I feel I am capable of doing*
24 *something I will do it. If I’m not capable, I won’t.” (PB133)*

25

1 Task persistence behaviour emerged among participants who completed tasks, despite
2 symptoms:

3

4 *“I just think I’ve got to get on with it and that’s it...if it hurts, well I will*
5 *stop eventually, but I’ll carry on until I’ve finished the task that I’m*
6 *doing.” (PB139)*

7

8 Frequently, a flare-up of symptoms was reported following excessive Task
9 persistence. This may relate to Task fluctuation (boom-bust) behaviour:

10

11 *“If you get up and you feel a lot better than you normally do, you push*
12 *yourself and then you suffer for it.” (PN240)*

13

14 Task modification behaviour involved implementing generally more consistent
15 activities to reduce a foreseen boom-bust pattern:

16

17 *“I used to run around like mad on a good day doing everything that I*
18 *possibly could, but then I’d have more bad days as a result of the good*
19 *days, so the balance wasn’t there. So, now I do make use of the good days*
20 *but I don’t over-do it and I try to stop before I’ve run myself into the*
21 *ground.” (RN318)*

22

23 Task modification appeared to involve implementing the different facets of pacing to
24 reduce the extremes of Task avoidance/Task persistence and cycling between the two
25 (Task fluctuation).

Discussion

Activity pacing is considered to be a multifaceted coping strategy, and this was verified during the interviews. Pacing was described as involving adjusting/reducing activities by breaking down tasks, using rest breaks and alternating activities; facets that are cited in the literature as key components of pacing [2,4,16,33,34]. Pacing was additionally reported as involving planning/prioritising activities and setting goals; in keeping with pacing literature [2,33,34]. The facet of gradually increasing activity levels divided participants' opinions: being relevant for some, but impossible for others. This replicates diverse opinions of pacing in the literature, both including and excluding activity progression [4,9,33-35]. Participants identified that pacing helped to reduce exacerbating symptoms by not over-doing activities on 'good' days, and some participants tried to engage in activity on 'bad' days. This concurs with the aim of pacing to reduce the overactivity-underactivity cycle [16]. Participants recognised that pacing may involve accepting activity levels, which agrees with pacing literature involving individuals' recognition of capabilities [16,34].

The multifaceted pacing description that emerged from the interviews endorsed the different pacing facets that were found in Stages I and II of the study. Participants suggested few additional facets of pacing that had not been included in the APQ following the Delphi technique [24]. Interestingly, these suggested additional facets were those that had not reached consensus in the Delphi technique when recruitment of patients had been lower than clinicians (*see Figure 1*). Therefore, there may be differences in opinions between clinicians and patients regarding some pacing facets.

The APQ-38 demonstrated general acceptability, and the items referred to 'symptoms'

1 (rather than ‘pain’ as in existing pacing subscales) which was found to be preferable.
2 However, the larger number of items in the APQ-38 was less favoured. The
3 interviews were based on all 38 original APQ items. However, 12 items have been
4 removed following scale refinement in the psychometric study. The telephone
5 interviews supported the removal of some items since they were reported to be
6 confusing, irrelevant or repetitive.

7

8 The majority of participants who implemented pacing reported that it was beneficial.
9 This agrees with findings of anecdotal support for pacing, albeit in the absence of
10 empirical evidence [6,8,35]. The implementation of pacing appeared to vary with
11 participants’ age, emotions and the presence of co-morbidities. It has been found
12 elsewhere that adherence to self-management strategies among patients with multi-
13 morbidities (≥ 2 LTC) is affected by their capacity (emotional/physical/financial),
14 responsibility (including self-efficacy) and motivation [36]; and depression has been
15 associated with poor adherence to medical recommendations [37]. Such factors may
16 play an important role in the uptake of pacing as a self-management strategy;
17 motivation previously suggested as an important factor involved in pacing [4].
18 Relationships between pacing and multi-morbidities, mood and self-efficacy warrant
19 future investigation.

20

21 Activity behaviours emerged from the interviews, including symptom/quota-
22 contingent behaviours. Four behaviour typologies emerged: Task avoidance, Task
23 persistence, Task fluctuation (boom-bust) and Task modification (activity pacing).
24 Notably, four behaviours were identified in cluster analyses of PARQ data: ‘avoiders’,
25 ‘doers’, ‘extreme cyclers’ and ‘medium cyclers’ [5]. Some differences are evident

1 between these behaviours and those of the present study. This may be due to
2 differences between the APQ and PARQ pacing subscale content; the PARQ
3 involving predominantly reducing activities.

4

5 *Strengths and limitations*

6 The sample size (n=16) was smaller than planned. However, the 16 interviews
7 generated a rich amount of qualitative data and towards the latter interviews data
8 saturation was concluded. Furthermore, the sample was not intended to be statistically
9 representative, but instead, purposefully selected to represent a heterogeneous group of
10 patients with chronic pain/fatigue.

11

12 Since the researcher undertook the interviews, there is potential for researcher bias.
13 However, this role enabled the researcher to be emerged in the qualitative data and to
14 assist the recognition of data saturation. The transparency and ease of data retrieval
15 was increased by implementing Framework analysis [31]. Furthermore, a second
16 researcher (LM) read the transcripts and commented on the analysis. This study
17 increased service-user involvement in the development of the APQ. This will
18 contribute to a more relevant and acceptable pacing scale.

19

20 *Conclusion*

21 Stage III of the APQ development found the scale was generally acceptable for
22 patients with chronic pain/fatigue. Future work will refine the APQ-26 to increase its
23 clinical utility and acceptability. Participants' descriptions of activity pacing echoed
24 the multifaceted nature of pacing contained in the APQ-26. Further research will
25 explore different behaviour typologies and the pacing facets that are implemented by

- 1 each typology. Ultimately, this would assist the development of individually tailored
- 2 pacing programmes.

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1

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5

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8

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11

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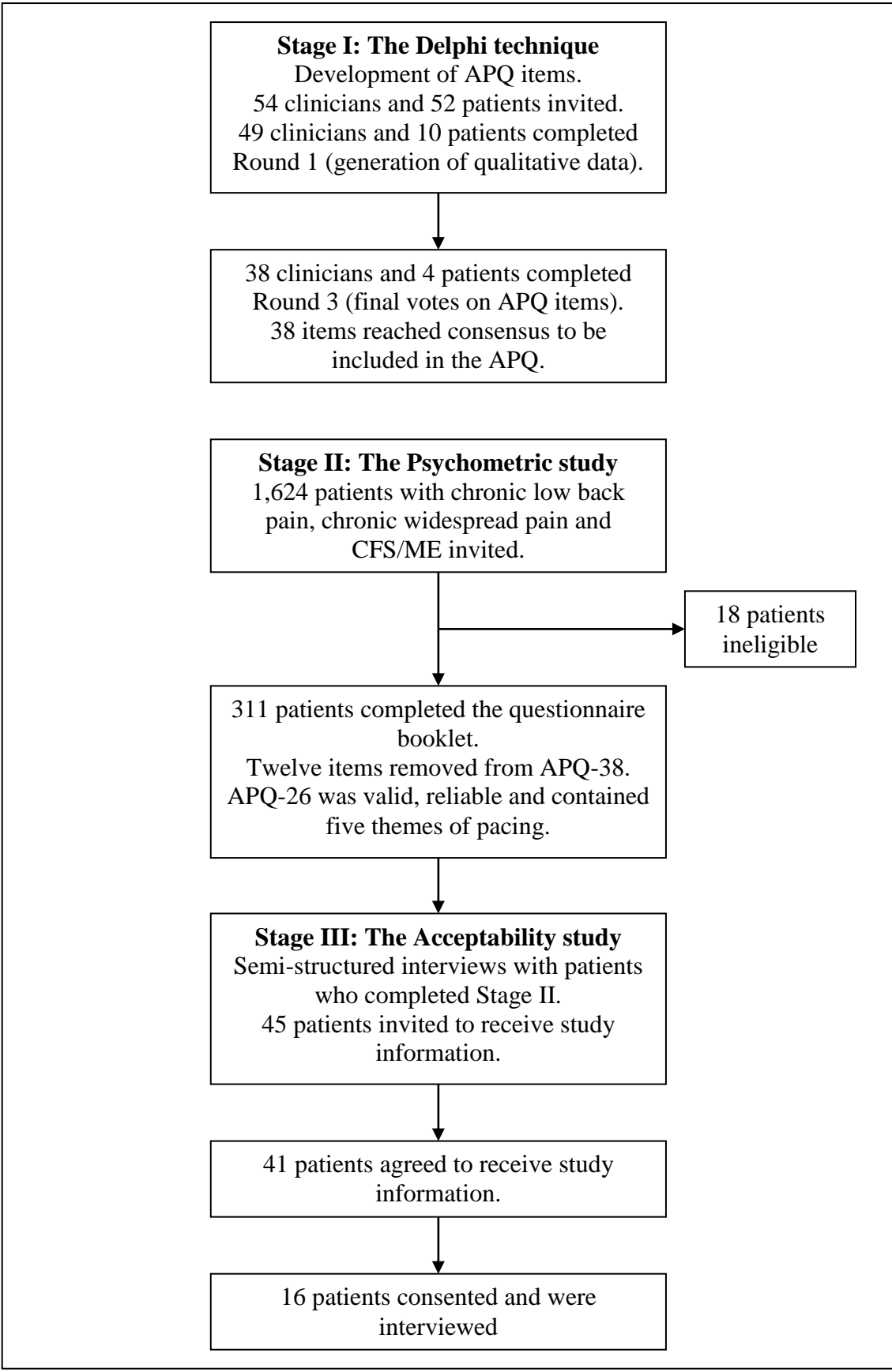
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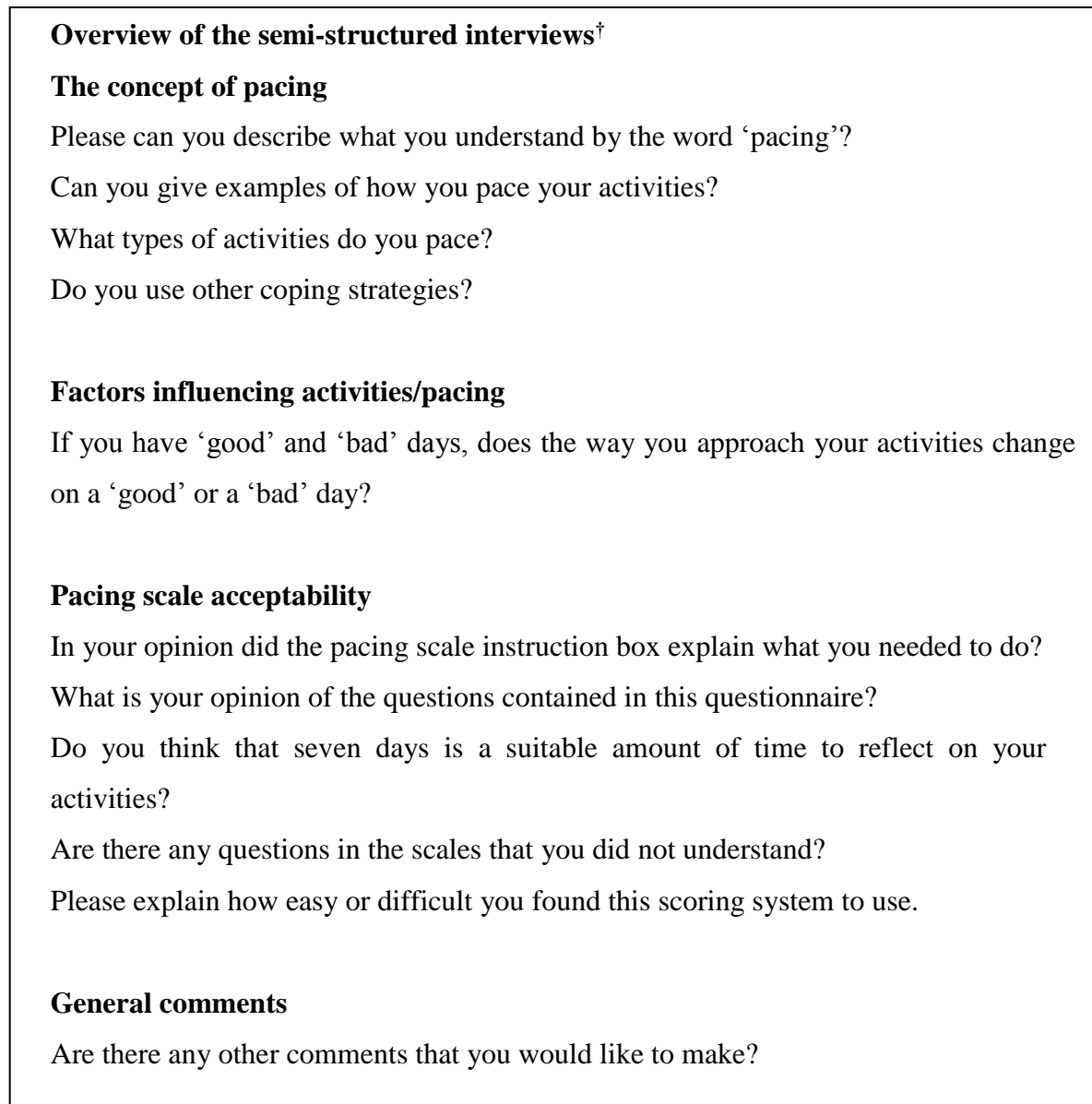
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44 Figure 1. Flow chart of recruitment into the mixed methods study to develop the
45 activity pacing questionnaire (APQ)

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5 Figure 2. Overview of the semi-structured interviews

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7 *†The specific format of each interview varied as per the nature of semi-structured*
8 *interviews; probing questions allowed further enquiry following interviewees’*
9 *comments.*

1 Table 1. Participants' demographic characteristics

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Characteristic		Male (n=4)	Female (n=12)	Total (n=16)
Age in years: range (mean)		24-68 (47.3)	25-73 (51.1)	24-73 (50.1)
Chronic low back pain*		4	8	12
Chronic widespread pain/ Fibromyalgia*		2	5	7
Chronic fatigue syndrome/ Myalgic encephalomyelitis (CFS/ME)*		1	3	4
Main condition*	Chronic low back pain	2	7	9
	Chronic widespread pain/Fibromyalgia	2	3	5
	CFS/ME	0	2	2
Duration of condition in years: range (mean)		4.0-15.0 (10.3)	2.0-40.0 (12.9)	2.0-40.0 (12.3)

3 *Participants could report more than one condition, but were also asked to select their
4 main condition.

1 Table 2. Examples of participants' comments and APQ-26 items that contain similar
 2 concepts

Example of participants' comments	Example of APQ-26 items
<i>"I'd break it up into manageable chunks. On a personal level that's usually about 20 minutes-half an hour, then have a rest for about the same period."</i> (PC100)	I broke tasks up into periods of activity and rest
<i>"It means little but often, instead of trying to do everything at once and making yourself worse."</i> (PC082)	I kept to a consistent level of activity
<i>"It's trying to get a balance between...the more stressful activities/the more demanding activities, and having some time to enjoy the activities that you want to do"</i> (RN318)	I did a variety of different activities
<i>"Ever since the physio I've been doing I've been able to push myself more and not feel any negative effects."</i> (PW048)	I gradually increased activities that I had been avoiding because of my symptoms
<i>"...assess what I can do and what I can't do."</i> (PN309)	I assessed my activity levels
<i>"...in terms of how much cleaning I would do around the house, I would set myself a more realistic achievement without being in pain."</i> (PG017)	I set activity goals that were realistic for me
<i>"I occasionally have to say 'no' to other people"</i> (PF011)	I was able to say 'no' if I was unable to do an activity

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