

BMJ Open Exploring strategies used following a group-based fatigue management programme for people with multiple sclerosis (FACETS) via the Fatigue Management Strategies Questionnaire (FMSQ)

S Thomas,¹ P Kersten,² P W Thomas,¹ V Slingsby,³ A Nock,³ R Jones,⁴
A Davies Smith,⁴ K T Galvin,⁵ R Baker,¹ C Hillier³

To cite: Thomas S, Kersten P, Thomas PW, *et al*. Exploring strategies used following a group-based fatigue management programme for people with multiple sclerosis (FACETS) via the Fatigue Management Strategies Questionnaire (FMSQ). *BMJ Open* 2015;5:e008274. doi:10.1136/bmjopen-2015-008274

► Prepublication history for this paper is available online. To view these files please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2015-008274>).

Received 22 March 2015
Revised 11 August 2015
Accepted 15 September 2015



CrossMark

For numbered affiliations see end of article.

Correspondence to

Dr Sarah Thomas;
saraht@bournemouth.ac.uk

ABSTRACT

Objectives: To explore cross-sectional patterns of use of fatigue management strategies in people with multiple sclerosis (MS) who had attended a group-based fatigue management programme, Fatigue: Applying Cognitive behavioural and Energy effectiveness Techniques to lifeStyle ('FACETS').

In a multicentre randomised controlled trial (RCT) the FACETS programme was shown to reduce fatigue severity and improve self-efficacy and quality of life.

Design: A questionnaire substudy within a RCT involving the self-completed Fatigue Management Strategies Questionnaire (FMSQ). The FMSQ includes: (1) closed questions about the use and helpfulness of fatigue management strategies taught in FACETS and (2) open items about changes to lifestyle, attitudes or expectations, barriers or difficulties encountered and helpful strategies not covered in FACETS.

Participants: All had a clinical diagnosis of MS, significant fatigue, were ambulatory and had attended at least 4 of 6 scheduled FACETS sessions.

Methods: Participants (n=72) were posted the FMSQ with a prepaid return envelope 4 months after the end of the FACETS programme.

Results: 82% (59/72) of participants returned the FMSQ. The fatigue management strategies most frequently used since attending FACETS were prioritisation (80%), pacing (78%), saying no to others (78%), grading tasks (75%) and challenging unhelpful thoughts (71%). Adding in those participants who were already using the respective strategies prior to FACETS, the three most used strategies at 4 months were prioritisation (55/59), grading (54/59) and pacing (53/58). Free-text comments illustrated the complex interplay between attitudes/expectations, behaviours, emotions and the environment. Issues related to expectations featured strongly in participants' comments. Expectations (from self and others) were both facilitators and barriers to effective fatigue management.

Strengths and limitations of this study

- This study was nested within a large pragmatic multicentre randomised controlled trial undertaken in the UK.
- It provides valuable insights into experiences of a complex group-based fatigue management intervention designed for people with multiple sclerosis (MS).
- Resource constraints meant that we were limited to a postal semistructured questionnaire rather than conducting interviews or focus groups. However, this might have reduced the likelihood of demand characteristics.
- Eighty-two per cent of the 72 participants who attended 4 or more sessions of the Fatigue: Applying Cognitive behavioural and Energy effectiveness Techniques to lifeStyle (FACETS) programme completed the Fatigue Management Strategies Questionnaire (FMSQ).
- The FMSQ was administered 4 months following the FACETS programme so we do not have information about participants' use of fatigue management strategies in the longer term.

Conclusions: Individuals' comments highlighted the complex, multifaceted nature of fatigue management. Revising expectations and a greater acceptance of fatigue were important shifts following the programme. Findings support the relevance of a cognitive behavioural approach for fatigue management. Booster sessions might be a useful addition to the FACETS programme.

Trial registration number: Current controlled trials ISRCTN76517470; Results.

INTRODUCTION

The Multiple Sclerosis Council for Clinical Practice Guidelines defines fatigue as "a

subjective lack of physical and/or mental energy that is perceived by the individual or caregiver to interfere with usual and desired activities.”¹ Fatigue is one of the most common and debilitating symptoms of MS; affecting up to 86% of people with MS, with two-thirds considering it to be one of their three worst symptoms.^{2–7} In the UK it has been reported that the prevalence of MS is increasing with an estimated 126 669 people living with MS in the UK in 2010 (203.4 per 100 000 population) and 6003 new cases diagnosed that year (9.64 per 100 000/year).⁸

Fatigue often occurs on a daily basis² and its invisible and unpredictable nature makes it a particularly frustrating symptom to cope with.⁹ The pathophysiology of MS-fatigue is poorly understood but is likely to be multifactorial making it a complex and challenging symptom to manage and treat.¹⁰ It has a profound impact on all spheres of daily life; limiting or preventing participation in work, leisure and social activities and reducing psychological well-being.¹¹ It is the primary reason why people with MS give up work or reduce their hours.¹² Currently diagnosis of MS is based on the revised McDonald criteria.¹³

The most common non-pharmacological treatment approaches for fatigue management include energy conservation/effectiveness, psychological approaches (such as cognitive-behavioural therapy (CBT) and mindfulness) and exercise.^{14 15} In the UK, the National Institute for Health and Care Excellence (NICE) clinical guidance for MS suggests that health professionals could consider mindfulness therapy, CBT or fatigue management and advise that aerobic balance and stretching exercises including yoga may be helpful in treating MS-related fatigue.¹⁶

Energy effectiveness approaches focus on using available energy in the most effective way possible; for example, by pacing, planning, grading, delegating, altering one's environment and so on. While such

approaches can be moderately helpful¹⁷ there are sometimes attitudinal barriers that stop individuals from applying them to aspects of their own routines and lifestyle. For example, a person might fully understand the rationale behind pacing activities or delegating them, yet not implement such strategies due to a belief that they are a failure unless they take on everything themselves and finish tasks in one go. Similarly, it might be feasible for an individual to change daily routines and schedule regular rests in their day, yet they may feel unable to give themselves ‘permission’ to do so due to feelings of laziness and/or guilt.¹⁸

A cognitive behavioural approach can be helpful in addressing these kinds of complex attitudinal barriers in the self-management of chronic conditions.^{19 20} Cognitive behavioural approaches are concerned with how thoughts, emotions, behaviours and physical and environmental aspects interact.^{21 22} They are based on the theory that sometimes changing how we think about a situation influences what we feel and do. In the examples given above, unless the thoughts and sometimes long-standing attitudes related to fatigue and its management are considered alongside the behaviours, emotions and lifestyle factors it might be difficult to bring about change.

We developed a 6-week manualised group-based fatigue management programme (FACETS—Fatigue: Applying Cognitive behavioural and Energy effectiveness Techniques to lifeSyle) that combines cognitive behavioural and energy effectiveness approaches to manage fatigue in people with MS¹⁸ (see [table 1](#)).

Each session includes facilitator-delivered presentations, flipchart discussions, group activities and homework. In addition, participants receive supplementary resources produced by national MS charities (examples include information about exercise,²³ nutrition²⁴ and living/coping with fatigue²⁵).

Table 1 Summary of content of FACETS sessions

Session	Title	Summary of content	Homework
1	What is MS-related fatigue?	General introduction; expectations, icebreaker (quiz); types of fatigue; contributory factors; conceptual model of fatigue in MS	Activity/fatigue diary
2	Opening an ‘energy account’	Rest (functions; barriers); relaxation types and techniques; sleep hygiene	Rest/sleep/activity planner; energy measure
3	Budgeting energy and ‘smartening up’ goals	Types of activity; balancing activity and rest; moderating activity; toolbox; lifestyle factors, (including exercise, diet); goal setting	Setting S.M.A.R.T. goals exercise
4	Stress and the CB model	Stress response; ways of coping with stress; introducing the CB model	‘Unhelpful thoughts related to fatigue’ diary
5	Putting unhelpful thoughts ‘on trial’	Unhelpful thought patterns; challenging unhelpful thoughts related to fatigue; levels of belief	Thought challenge sheet
6	Recapping and taking the programme forward	Revisiting expectations; introducing the ‘forcefield’; group activity to revisit programme themes; ‘Keeping on Track’ planner	‘Keeping on track’ planner

CB, cognitive behavioural; MS, multiple sclerosis; S.M.A.R.T., ‘Specific; Measurable; Achievable; Realistic; Time for review’.

In the programme there is a gradual transition from a practical to a more psychological orientation. However, CB elements (thoughts, emotions, behaviours, physical aspects, environment) are introduced early, enabling participants to explore their reciprocal links, before the CB model is formally introduced in session 4. This approach was taken as sometimes individuals can find the CB model daunting and we wanted participants to have the opportunity to become familiar with and explore the CB components via group activities before formally introducing the model.

The effectiveness of FACETS was demonstrated in a randomised controlled trial with improvements (small-to-medium effect sizes) in fatigue self-efficacy, fatigue severity and quality of life up to 1 year postintervention.^{26–28} Exploring why and how complex interventions work can enhance further development and implementation and inform the design of future interventions.²⁹ In this paper we explore via a semistructured self-reported questionnaire whether, at 4 months follow-up, participants who attended the FACETS programme had made any changes to their attitudes, lifestyle or behavioural routines, whether these changes had been successful or not and the reasons why.

METHODS

All participants gave written informed consent before taking part.

Participants

Participants were people with MS enrolled in the FACETS randomised controlled trial who had been allocated to the FACETS arm. Inclusion criteria for the trial are described in full in the published protocol and trial papers,^{26–28} but in brief, included having a clinical diagnosis of MS, fatigue impacting on daily life, and being ambulatory (<8 on the Adapted Patient Determined Disease Steps (APDDS) Scale³⁰).

Fatigue: Applying Cognitive behavioural and Energy effectiveness Techniques to lifeStyle

This 6-week group-based manualised fatigue management programme combines cognitive behavioural and energy effectiveness approaches. The aim of the programme is to help people normalise their fatigue experiences, learn helpful ways of thinking about fatigue and use their available energy more effectively. It is delivered in groups of 6–12 people by two health professionals (such as occupational therapists, nurses or physiotherapists) with experience of MS-fatigue, of facilitating group-work and an awareness of cognitive behavioural principles. Further detail can be found elsewhere.¹⁸

The Fatigue Management Strategies Questionnaire (FMSQ)

As part of the trial we developed a semistructured questionnaire, called the FMSQ. As the aim of this evaluation questionnaire was to gain insights into the strategies

people used following the FACETS programme rather than create an outcome measure, a full psychometric evaluation has not been conducted. The format of the FMSQ draws on an existing psychometrically validated questionnaire (The Energy Conservation Strategies Survey).^{31 32} The FMSQ comprises 14 self-reported questions incorporating a combination of closed and open response formats. The initial draft of the questionnaire was developed by ST and PWT with content informed by findings from our development work.¹⁸ Development of the questionnaire underwent a number of iterations with feedback from researchers, clinicians and service users. Questions 1–11 ask participants whether they have started using 11 specific fatigue management strategies since attending the FACETS programme (namely, (1) pacing, (2) relaxation techniques, (3) changing the way activities are prioritised, (4) grading activities to save energy, (5) delegating activities, (6) planning ahead/organising activities, (7) saying no to others, (8) goal-setting, (9) starting any new exercise activities, (10) making changes to sleep routines and (11) challenging unhelpful thoughts). For strategies tried, participants are asked to rate how helpful they have found them on a 7-point scale (1=not at all helpful; 7=very helpful), and for those not tried, they are asked to indicate reasons why ('already doing' (this category was not used for questions (9) and (10) as these items specifically asked about whether changes had been made), 'forgot to try', 'didn't think would help', 'unsure how to do', 'other; please specify'). Results from individual items will not be combined except to count the total number of strategies used by participants.

The second part of the questionnaire consists of a number of items using a free-text response format and asks participants to describe any (1) changes made to their lifestyle, attitudes or expectations since attending the FACETS programme (reflecting key aims of FACETS identified from our development work); (2) barriers to change or difficulties encountered; (3) fatigue management strategies that they had found helpful but that were not covered in the programme. We also asked respondents if they had been in contact with other group members since the FACETS programme.

It is important to note that FACETS is a complex and multicomponent intervention and the FMSQ focuses on fatigue management strategies and attitudinal changes but does not specifically ask people about awareness or normalisation of MS-fatigue, the group-based nature of the programme or the homework tasks. The questionnaire is presented in an easy to read font (pt.13.5). The instructions for the questionnaire are as follows:

During the fatigue management programme you were taught a number of strategies to help you to make the most of your available energy. We are interested to find out whether you are using any of these strategies, and if so, whether you have found them helpful.

We are also interested in the reasons why you might have found it difficult to make changes.

The questionnaire was posted to participants 4 months after the final session of the FACETS programme. Respondents were asked to return the completed anonymised questionnaire to the trial team using a prepaid return envelope.

Analysis

We collated free-text responses. Quantitative data from the questionnaire were analysed descriptively using frequencies, percentages, medians and ranges.

An iterative, directed approach to content analysis was used.³³ After careful reading and data immersion ST coded all the free-text comments and developed broad categories. These were subsequently revised following discussion with one of the coauthors (PK) and verified by the other coauthors. Respondents' comments have been organised based on the cognitive behavioural framework as follows: (1) *what we do* (behaviours); (2) *how we think* (thoughts); (3) *how we feel* (feelings); (4) *our body* (physical); and (5) *our world* (environment). However, we note that often these overlap.

RESULTS

Of the 84 participants allocated to the FACETS arm, 72 (86%) attended 4 or more of the 6 scheduled weekly sessions. In table 2 we provide some background demographic and MS-specific data for this subsample that were gathered as part of the FACETS trial. The reasons why 12 people attended either no sessions (n=10) or 1 session only (n=2) are provided in the CONSORT diagram of the trial paper.²⁷

In total, 59 FMSQs were completed (42 female respondents; 17 male) at 4 months follow-up (82% of those 72 participants who attended 4 or more sessions). Descriptive statistics for questionnaire returners and non-returners are presented in table 1. Of the 13 who did not return the FMSQ, session attendance was: 4 sessions, n=1; 5 sessions, n=6; 6 sessions, n=6.

Fatigue management strategies

Of the 11 possible fatigue management strategies listed, the median number started or used since the programme was eight, with 81% of respondents reporting that they had started to use at least a half of them (table 3).

The fatigue management strategies that participants had most commonly started to use since the end of the programme were: prioritisation, pacing, saying 'no', grading tasks and challenging unhelpful thoughts. Adding in those people who were already using a respective strategy prior to the programme, the three most used strategies were prioritisation (55/59), grading tasks (54/59) and pacing (53/58). Planning and exercise were already being used by approximately one-

Table 2 Descriptive statistics for demographic and baseline characteristics of participants who attended four or more sessions of the six session FACETS programme

	Returned FMSQ N=59	Did not return FMSQ N=13*
Gender (n (%))		
Female	42 (71%)	11 (85%)
Male	17 (29%)	2 (15%)
Age (years)		
Mean (SD)	48.5 (9.7)	48.8 (14.2)
Range	33–73	23–70
Self-reported disease type (n (%))		
Benign	4 (7%)	–
Relapsing–remitting	25 (42%)	5 (42%)
Secondary progressive	14 (24%)	–
Primary progressive	2 (3%)	2 (17%)
'Do not know'	14 (24%)	5 (42%)
APDDS score (Adapted Patient Determined Disease Steps) (n (%))		
3 or less (no limitations in walking)	17 (29%)	0 (0%)
4 or 5 (MS interferes with walking)	23 (39%)	10 (83%)
6 or more (at minimum, needs stick/crutch to walk 100 m)	19 (32%)	2 (17%)
Employment status (n (%))		
Employed	18 (31%)	6 (50%)
Not in paid employment (unemployed, in education, retired, looking after home)	41 (69%)	6 (50%)
Years since diagnosis (n (%))		
5 or fewer	22 (37%)	6 (50%)
6–10	9 (15%)	4 (33%)
11–15	18 (31%)	1 (8%)
>16	9 (15%)	1 (8%)
Not stated	1 (2%)	–

Percentages rounded to nearest integer, and thus, might not sum exactly to 100%.

*Missing data for one case on some characteristics.

FMSQ, Fatigue Management Strategies Questionnaire.

quarter of participants, and 17% of respondents reported that they forgot to try goal-setting. Of those who had started to use a strategy, the median rating of helpfulness was either 5 or 6 (out of a maximum of 7).

As part of the FACETS trial we gathered a range of self-reported outcomes. The mean (SD) fatigue score on the Global Severity Subscale of the Fatigue Assessment Instrument³⁴ for the 59 participants who completed the FMSQ was 5.5 (1.0) at baseline and 5.3 (0.9) at 4 months, p=0.01 using the paired samples t test. We used independent samples t tests to compare the mean change in fatigue (score on the Global Fatigue Severity Subscale of the FAI) from baseline to 4 months follow-up of those who had started a fatigue management strategy versus those who had not for each of the

Table 3 Results from the Fatigue Management Strategies Questionnaire (n=59)

Strategy	Started using as a result of FACETS? N (%)			If yes, how helpful? (1=not at all 7=very) Median, Range	If no, reason why				
	Yes	No	Not stated		Already doing	Forgot to try	Didn't think would help	Unsure how to do	Other
Prioritising differently	47 (80%)	12 (20%)	–	6, 2–7	8	2	–	–	2
Pacing	45 (78%)	13 (22%)	1	6, 3–7	8	1	1	–	3
Saying no to others	45 (78%)	13 (22%)	1	5, 2–7	6	–	–	3	4
Grading tasks	44 (75%)	15 (25%)	–	6, 3–7	10	2	–	–	3
Challenging unhelpful thoughts	42 (71%)	17 (29%)	–	5, 3–7	6	3	1	2	5
Relaxation Techniques	39 (66%)	20 (34%)	–	5, 2–7	8	5	4	1	2
Delegation	37 (63%)	22 (37%)	–	5, 2–7	9	1	1	–	11
'SMART' goals*	34 (59%)	24 (41%)	1	5, 2–7	5	10	4	1	4
Sleep hygiene	34 (58%)	25 (42%)	–	5, 2–7	–	1	8	–	16
Planning ahead	32 (55%)	26 (45%)	1	5, 3–7	15	1	6	–	4
New exercise activities	28 (48%)	30 (52%)	1	6, 2–7	–	3	1	5	21†

*SMART stands for 'Specific; Measurable; Achievable; Realistic; Time for review'.

†14/21 of the 'other' responses indicated that the person was already doing exercise.

11 strategies included in the FMSQ. None of these differences was statistically significant. The Pearson correlation coefficient between mean change in fatigue with total number of strategies used was low and not significant ($r=-0.01$ (95% CI $-0.28, 0.25$), $p=0.93$). The Kuder-Richardson-20 Formula (KR-20) reliability coefficient for the 11 dichotomous items relating to fatigue management strategies was 0.76.³⁵

Twenty-three of the 59 respondents reported having been in contact with one or more group members following the FACETS programme. The majority of these contacts involved email or social media but four respondents reported telephone contact and seven respondents had met with up with one or more from the group. Sometimes this involved meeting up to do activities together (eg, yoga, physiotherapy, theatre visits).

There was a good level of response to the free-text items on the FMSQ (table 4) and these data were consistent with the quantitative data. The fatigue management strategies described most frequently by respondents related to resting, pacing, delegating, prioritising and saying no to others.

What we do (behaviours)

Respondents noted how using strategies such as those in Box 1 could help to change priorities and provide more opportunities for enjoyable, valued activities:

I have definitely tried and sometimes succeeded in taking planned rest periods. This has allowed me to gain more enjoyment from social activities. (ID067)

However, some respondents reported practical barriers to implementing fatigue management strategies related to the messiness of 'real life' such as the challenges of resting within the work setting, a lack of support from others, hectic lives and time pressures, unplanned events, major life events (such as moving house), work and family commitments, money issues and lack of suitable exercise facilities/informed staff:

Real life doesn't always go to plan and even when events fit nicely on a planner chart, with rests planned in—things just happen and throw carefully planned days into disorder so I'm learning to 'go with the flow more and more'. (ID006)

Table 4 Number of participants responding to the free-text items in the Fatigue Management Strategies Questionnaire

Free-text items	Free-text response	'No' or 'none'	Left blank
If you have made any changes since attending the fatigue programme either to your lifestyle, attitudes or expectations, please describe them below.	48	2	9
Please describe any barriers to change, or difficulties that you have encountered.	44	4	11
Are there any strategies that you have found helpful for managing fatigue that were not covered in the fatigue management programme?	14	18	27

Box 1 Examples of strategies that participants reported as helpful

- ▶ I allow myself to rest as soon as needed, then complete my task later. (ID037)
- ▶ Naps are a daily routine now and useful. (ID158)
- ▶ I do try to pace myself especially at home and sit down when ironing to conserve energy. (ID002)
- ▶ I make sure that I have regular breaks now instead of pushing myself until I am exhausted. (ID062)
- ▶ I now do not try and do all the housework in one hit. (ID023)
- ▶ Whereas before I was working like an idiot during my good time of the day. I rest during the morning and am not so tired pm. (ID098)
- ▶ I think delegating has helped a lot. Cleaning cooking, walking dog. (ID095)
- ▶ I have put a lot more thought into how I was going to do things prior to doing so. (ID127)
- ▶ I don't make long-term plans. I am more spontaneous. If I have a good day I do something. (ID097)
- ▶ Continuing with yoga exercises and attending the gym which appears to give more energy for other activities. (ID039)

I still work full time which I love but [*fatigue management*] can be hard due to work commitments and demands sometimes. I do try to get a balance but not always possible. (ID115)

How we think (thoughts)

In terms of helpful changes made since the programme, respondents reported modifying their thoughts related to expectations and becoming less self-critical:

Admit to myself that I'm not a failure if I can't do something. (ID035)

One person described a process of 'stepping back' to gain a new perspective:

I can't carry out a job to the level and standard I wish to and so I have decided to take a step back. (ID081)

Others described a change in their approach to situations:

I've tried to limit the things I 'must' do in favour of what I want to do. (ID037)

Conversely, some respondents described their own expectations as a key barrier to change:

My own reluctance to 'give in' which often results in my overdoing it to the point of inducing severe fatigue which exacerbates other symptoms. (ID104)

How we feel (feelings)

Some respondents described no longer feeling guilty about not being able to do all they used to do and feeling more comfortable about asking for help:

I'm no longer embarrassed about asking for help from others—even when going shopping in my wheelchair and surprise, surprise, people are happy to help. (ID006)

The theme of expectations was closely linked with 'acceptance'. Acceptance was described as a challenging, ongoing process:

Physically I have expected to act and cope as a normal person. However, in the last 10 years fatigue has become progressively worse and I am now acknowledging this. It still doesn't stop me feeling lazy but I accept it more. (ID024)

Our body (physical)

People reported that memory difficulties, medication side effects, relapses and illness at times impacted and developed strategies in relation to this:

One of the biggest barriers is being acknowledged, having it accepted that you know your body and mind as an individual and that fatigue is to be taken seriously and worked with, not against. (ID029)

Our world (environment)

Participants described various ways of modifying aspects of their environment including delegating and grading tasks and using energy saving devices (such as going shopping using a wheelchair).

Others' expectations were noted as a potential barrier to effective fatigue management and something that needed to be managed:

People expect me to still do everything I used to and don't seem to hear the word 'no'. (ID097)

I find it very difficult to 'say no' as people seem very disappointed when they are turned down. Also at work when I turn down work hours I always feel very guilty. (ID038)

One person commented that since attending FACETS she felt less concerned about others' expectations and only felt a need to push herself for family and close friends:

I feel now that I have to prove myself less to others and it is OK to say no. The only people I feel I have to push myself for are family and close friends. (ID006)

Others described the challenges arising from others' lack of understanding of MS and the invisible nature of symptoms such as fatigue:

I find people do not understand the condition MS and when with family groups (not my husband or daughter) I feel as if people think I am lazy. (ID002)

Another person made the observation that making changes might impact positively on the attitudes and behaviours of those around:

If I try, then so will others. And with that comes greater understanding. (ID098).

Multifaceted approach to fatigue management

Fatigue management strategies were often used in combination, underlining the need for a multifaceted approach towards fatigue management; for example, the person below describes how they have modified their expectations and values and how this has enabled them to use fatigue management tools such as delegation and pacing:

Working full time means I only have the weekend to clean top to bottom. Before I attended the programme it had to be done all in one go, now I delegate some of the cleaning to others in the house or spread the cleaning over two days. (ID023)

Respondents' comments illustrated the links between attitudes/expectations, behaviours and emotions:

The course made me realise I didn't have to feel guilty for not being able to do everything I used to do. I've learnt to say no. I've slowed down and am able to lie down in the afternoon and relax. (ID097)

Fatigue management was described as an ongoing process that would not be achieved overnight and a process that could be revisited:

Now that things have settled down I am going to revisit the whole programme over the coming months and start to work in more of the techniques. (ID081)

For some a significant aspect of the FACETS programme was the confirmation that MS-fatigue is "*different from normal tiredness*" (ID104) and a major symptom of MS. People described increased awareness about the causes of fatigue and possible strategies for reducing its impact:

I was surprised to find that exercise reduced my fatigue and also environmental changes (heat and light). (ID072)

While the programme information was not new to some people it was still considered useful in terms of clarifying certain aspects of fatigue management, reinforcing strategies already being used, and providing a helpful framework:

After having MS for 30 'odd' years I have developed many of the strategies myself, but the course helped me clarify aspects of activity etc. and put these into a more formalised arrangement (ID043).

Only 14 people responded to the FMSQ question about helpful strategies not covered in FACETS with comments relating to specific activities (e.g. horseriding, singing, yoga) or general feedback:

It was very helpful to me. I learnt a lot and it has made my life SO much easier. I would recommend it to anyone. I have also found what I learnt helpful to others with MS, mainly 'newly diagnosed' at MS newbie meetings. It makes

me feel great to be helpful and give advice to others with fatigue problems. I was there once! (ID098).

DISCUSSION

Our data suggest that 4 months following FACETS the majority of respondents were implementing some of the strategies covered within the programme. Successful changes encompassed not only those relating to behaviours (such as pacing) and the environment (such as delegating, grading tasks, using energy saving devices) but also attitudes and emotions ('I didn't have to feel guilty'; 'learning to admit to myself that I'm not a failure if I can't do something'). Feedback from respondents illustrated the complex interplay between attitudes/expectations, behaviours, emotions, physical aspects and the environment.

FACETS is a complex intervention involving multiple components to address a complicated symptom. The trial data indicated that the intervention is effective at helping people manage their fatigue. The current paper highlights that people used variable patterns of strategies (differing numbers and combinations) and that the degree to which they were helpful also varied. For example, participants could potentially have started multiple strategies and found only one useful; or started multiple strategies all of which were slightly helpful; or started only one strategy that was very helpful. Interpretation of our observed lack of association between changes in fatigue and use of individual strategies or total number of strategies used is therefore not straightforward and it is perhaps not surprising, given this complexity and the variable patterns of fatigue management that emerged from the data, that no clear associations were evident. Further research is needed to disentangle these complex relationships.

The theme of expectations featured strongly in respondents' comments. Changing expectations by challenging and restructuring unhelpful thoughts is a key tenet of the cognitive behavioural approach.^{21 22 36} Revising expectations and becoming more accepting or realistic about one's limits can enable people to give themselves 'permission' to make important lifestyle changes (such as saying no to others, taking rests, delegating responsibilities, pacing activity, adjusting priorities). However, modifying expectations is by no means an easy process with some respondents describing a resistance and reluctance to change, despite recognising potential benefits. A lack of understanding by or unrealistic expectations (or perceived expectations) of others, including family members, were identified as factors making fatigue management challenging. The invisible nature of fatigue and its variability can make it difficult even for family members and close friends to understand^{9 10} and this has also been reported in other neurological conditions.^{37 38}

In a cross-sectional questionnaire study Besharat *et al*³⁹ found an association between negative perfectionism and fatigue symptoms in people with MS. Such

perfectionism may reflect denial or an attempt to maintain a sense of self and identity in the face of an unpredictable and challenging chronic condition³⁹ and may lead to boom-or-bust patterns of behaviour.⁴⁰ Some of the free-text comments provided by respondents on the FMSQ reflected similar issues. The FACETS programme supports individuals to identify and challenge these kinds of unhelpful and unrealistic expectations.¹⁸

FACETS is delivered in a group format. In the context of an energy conservation course Matuska *et al*,³¹ noted that the group format enabled participants to share ideas and they were able to give and receive peer support. They found that many groups continued to meet informally following the completion of the course. Similarly in the context of a CB programme for rheumatoid arthritis Dures *et al*⁴¹ reported that participants highly valued the group format. We too, have consistently found similar highly positive feedback about the group format from FACETS participants.¹⁸ Additionally, around 40% of respondents reported some form of contact with other group members following FACETS. However, it must be noted that this feedback does not incorporate the views of those who declined to take part in the FACETS trial. While a group delivered format offers many benefits in terms of peer support and potential cost-effectiveness it does not suit everyone and must be considered as one of a range of interventions for people with MS-fatigue.^{15 16}

A major strength of this study is that it was nested within a large multicentre pragmatic UK trial. Return rates of the FMSQ were high (82%). However, resource constraints meant that we were unable to conduct any interviews or gather further detail or clarification from respondents. The semistructured questionnaire was administered at 4 months follow-up only so we do not have information about participants' use of fatigue management strategies in the longer term. Additionally, we acknowledge that more participants at 4 months follow-up may have started on disease modifying drugs or had a relapse given that these were exclusion criteria for the trial and would not be occurring at baseline. The majority of participants who completed the questionnaire were not in employment and we note that there may be important differences in relation to employment status in terms of opportunities to apply fatigue management strategies and the nature of the barriers and challenges faced. We also acknowledge the possibility of recall bias (ie, people forgetting strategies they have used) in participants' responses to the FMSQ at 4 months follow-up.

There are similarities between the feedback provided by our respondents and individuals who had attended a fatigue management programme for rheumatoid arthritis (RA). Dures *et al*⁴¹ conducted 'exit' focus groups with 38 participants who had attended a group-based cognitive behavioural programme for RA-fatigue. They reported that some people had moved from waiting for an external cure (a 'magic bullet') to a position of acceptance and understanding of the possibilities of self-help:

You might not be able to control the fatigue, you know that's going to be there, it's the feature of this condition but you can control how you manage it.⁴¹

When developing FACETS¹⁸ and in the current study we found similar shifts in perspectives:

Before I used to battle with it [*fatigue*], convinced that I could beat it. . .but since taking this course I've realised that perhaps I can't beat it, I can manage it.¹⁸

Overall, responses to the FMSQ suggested that the content of the FACETS programme had resonated with participants, whose comments demonstrated assimilation of information, as well as adherence to some of the key principles. Participants reported finding different aspects of the programme helpful, and implemented a range of strategies in varying combinations. This illustrates the importance of a multicomponent intervention in the context of a fluctuating and multifactorial symptom such as MS-fatigue.

Four months after the end of the FACETS programme the majority of attendees reported successfully implementing fatigue management strategies. While respondents noted some ongoing barriers to fatigue management it is encouraging that they were aware of such barriers and were able to identify and describe them. We propose that booster sessions might be a helpful addition to the FACETS programme to enable a facilitated review of progress and barriers encountered. The findings from this study highlight that fatigue management does not take place in isolation. The demands of everyday life are complex and varied and effective fatigue management often requires negotiating complex social, familial and work contexts/expectations as well as overcoming sometimes deeply entrenched and long-standing attitudinal barriers. This study provides valuable insights into people's experiences of a complex intervention for MS-fatigue management and supports the relevance of a cognitive behavioural approach. To obtain a copy of the FMSQ please contact the corresponding author.

Author affiliations

¹Clinical Research Unit, Faculty of Health and Social Sciences, Bournemouth University, Bournemouth, Dorset, UK

²Centre for Person Centred Research, School of Clinical Sciences, Auckland University of Technology, Auckland, New Zealand

³Dorset MS Service, Poole Hospital NHS Foundation Trust, Poole, UK

⁴MS Research Unit, Bristol and Avon MS Clinical Centre, Southmead Hospital, Bristol, UK

⁵Faculty of Health and Social Care, University of Hull, Hull, Yorkshire, UK

Twitter Follow Sarah Thomas at @SThomasBU

Acknowledgements Thanks to all the participants who took part and to the clinicians who identified the potential participants for the trial across the Trusts and primary care sites (Poole Hospital NHS Foundation Trust, University Hospitals Bristol NHS Foundation Trust, North Bristol NHS Trust, Southampton University Hospitals NHS Trust, Southampton City Primary Care Trust, Portsmouth Hospitals NHS Trust). Thanks for support from the Comprehensive Clinical Research Network and the Primary Care Network. Thanks to Ms Felicity Burgess for supporting recruitment at the Southampton

centre. Thanks to Dr Sara Demain, Mrs Caroline Birch, Ms Charlie Ewer-Smith, Mrs Jo Killeff, Mrs Jenn Gash and Mrs Sheila Chartres for delivering FACETS. Thanks to Mr Geoff Linder and Mr Tim Worner for patient and public involvement.

Contributors ST, PWT conceived the study. ST and PWT created the initial draft of the FMSQ and other members of the research team and service users (TW, GL) provided feedback. ST postally administered the questionnaire. ST, PK, PWT analysed the FMSQ data. ST produced an initial draft of the manuscript. PK and PWT contributed to the draft and all other authors critically reviewed and approved the final version. AN, VS and ADS delivered the fatigue management programme in their centres during the trial. CH provided clinical oversight during the trial.

Funding This work was supported by the Multiple Sclerosis Society in the UK (grant reference number 846/06). The trial is included in the National Institute of Health Research Clinical Research Network (NIHR CRN) portfolio (ID 4843). The trial was sponsored by Poole Hospital NHS Foundation Trust.

Competing interests None declared.

Ethics approval South West-Central Bristol Research Ethics Committee (ref: 08/H0106/2).

Provenance and peer review Not commissioned; externally peer reviewed.

Data sharing statement No additional data are available.

Open Access This is an Open Access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited and the use is non-commercial. See: <http://creativecommons.org/licenses/by-nc/4.0/>

REFERENCES

- Fatigue Guidelines Development Panel of the Multiple Sclerosis Council for Clinical Practice Guidelines. *Fatigue and multiple sclerosis. Evidence-based management strategies for fatigue in multiple sclerosis*. Washington DC: Paralyzed Veterans of America, 1998.
- Brañas P, Jordan R, Fry-Smith A, et al. Treatments for fatigue in multiple sclerosis: a rapid and systematic review. *Health Technol Assess* 2000;4:1–61.
- Kos D, Kerckhofs E, Nagels G, et al. Origin of fatigue in multiple sclerosis: review of the literature. *Neurorehabil Neural Repair* 2008;22:91–100.
- Lee D, Newell R, Ziegler L, et al. Treatment of fatigue in multiple sclerosis: a systematic review of the literature. *Int J Nurs Pract* 2008;14:81–93.
- Warner R. Fatigue in multiple sclerosis: our evolving understanding of the concepts. *Br J Neurosci Nurs* 2012;8:113–21.
- Induruwa I, Constantinescu CS, Gran B. Fatigue in multiple sclerosis —a brief review. *J Neurol Sci* 2012;323:9–15.
- Charvet L, Serafin D, Krupp LB. Fatigue in multiple sclerosis. *Fatigue Biomed Health Behav* 2014;2:3–13.
- Mackenzie IS, Morant SV, Bloomfield GA, et al. Incidence and prevalence of multiple sclerosis in the UK 1990–2010: a descriptive study in the General Practice Research Database. *J Neurol Neurosurg Psychiatry* 2014;85:76–84.
- White CP, White MB, Russell CS. Invisible and visible symptoms of multiple sclerosis: which are more predictive of health distress? *Neurosci Nurs* 2008;40:85–95, 102.
- Smith C, Hale L. The unique nature of fatigue in multiple sclerosis: prevalence, pathophysiology, contributing factors and subjective experience. *Phys Ther Rev* 2007;12:43–51.
- Costello K, Harris C. Differential diagnosis and management of fatigue in multiple sclerosis: considerations for the nurse. *J Neurosci Nurs* 2003;35:139–48.
- Raggi A, Covelli V, Schiavolin S, et al. Work-related problems in multiple sclerosis: a literature review on its associates and determinants. *Disabil Rehabil* 2015: Early Online: 1–9.
- Polman CH, Reingold SC, Banwell B, et al. Diagnostic criteria for multiple sclerosis: 2010 revisions to the McDonald criteria. *Ann Neurol* 2011;69:292–302.
- Bralely TJ, Chervin RD. Fatigue in multiple sclerosis: mechanisms, evaluation and treatment. *Sleep* 2010;33:1061–7.
- Hourihan SJ. Managing fatigue in adults with multiple sclerosis. *Nurs Stand* 2015;29:51–8.
- National Institute for Health and Care Excellence. *Multiple sclerosis: management of multiple sclerosis in primary and secondary care. Clinical Guideline No. 186*. London: NICE, 2014.
- Blikman LJM, Huisstede BMA, Kooijmans H, et al. Effectiveness of energy conservation treatment in reducing fatigue in multiple sclerosis: a systematic review and meta-analysis. *Arch Phys Med Rehabil* 2013;94:1360–76.
- Thomas S, Thomas PW, Nock A, et al. Development and preliminary evaluation of a cognitive behavioural approach to fatigue management in people with multiple sclerosis. *Patient Educ Couns* 2010;78:240–9.
- van Kessel K, Moss-Morris R. Understanding multiple sclerosis fatigue: a synthesis of biological and psychological factors. *J Psychosom Res* 2006;61:583–5.
- Dures E, Hewlett S. Cognitive-behavioural approaches to self-management in rheumatic disease. *Nat Rev Rheumatol* 2012;8:553–9.
- Beck JS. *Cognitive behavior therapy: basics and beyond*. 2nd edn. New York, NY: The Guilford Press, 2011.
- White C. *Cognitive behaviour therapy for chronic medical problems: a guide to assessment and treatment in practice*. Chichester: Wiley, 2001.
- MS Society. *MS essentials 21: exercise and physiotherapy 2013*. 2nd edn. London: MS Society, 2013.
- MS Society. *MS essentials 11: diet and nutrition 2012*. 4th edn. London: MS Society, 2013.
- Ennis M, Webster S. *Living with fatigue*. MS Trust London, 2015.
- Thomas PW, Thomas S, Kersten P, et al. Multi-centre parallel arm randomised controlled trial to assess the effectiveness and cost-effectiveness of a group-based cognitive behavioural approach to managing fatigue in people with multiple sclerosis. *BMC Neurol* 2010;10:43.
- Thomas S, Thomas PW, Kersten P, et al. A pragmatic parallel arm multi-centre randomised controlled trial to assess the effectiveness and cost-effectiveness of a group-based fatigue management programme (FACETS) for people with multiple sclerosis. *J Neurol Neurosurg Psychiatry* 2013;84:1092–9.
- Thomas PW, Thomas S, Kersten P, et al. One year follow-up of a pragmatic multi-centre randomised controlled trial of a group-based fatigue management programme (FACETS) for people with multiple sclerosis. *BMC Neurol* 2014;14:109.
- Atkins S, Odendaal W, Leon N, et al. Qualitative process evaluation for complex interventions. In Richards DA, Hallberg IR, eds. *Complex interventions in health: an overview of research methods*. Abingdon: Routledge, 2015.
- Orme M, Kerrigan J, Tyas D, et al. The effect of disease, disability and relapses on the utility of people with multiple sclerosis in the UK. *Value Health* 2007;10:54–60.
- Matuska K, Mathiowetz V, Finlayson M. Use and perceived effectiveness of energy conservation strategies for managing multiple sclerosis fatigue. *Am J Occup Ther* 2007;61:62–9.
- Mallik PS, Finlayson M, Mathiowetz V, et al. Psychometric evaluation of the energy conservation strategies survey. *Clin Rehabil* 2005;19:538–43.
- Hsieh H, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res* 2005;15:1277–88.
- Schwartz JE, Jandorf L, Krupp L. The measurement of fatigue: a new instrument. *J Psychosom Res* 1993;37:753–62.
- Kuder GF, Richardson MW. The theory of the estimation of test reliability. *Psychometrika* 1937;2:151–60.
- Beck AT. *Cognitive therapy and the emotional disorders*. New York: International Universities Press, 1976.
- Eilertsen G, Ormstad H, Kirkevoid M. Experiences of poststroke fatigue: qualitative meta-synthesis. *J Adv Nurs* 2013;69:514–25.
- Eilertsen G, Ormstad H, Kirkevoid M, et al. Similarities and differences in the experience of fatigue among people living with fibromyalgia, multiple sclerosis, ankylosing spondylitis and stroke. *J Clin Nurs* 2015;24:2023–34.
- Besharat MA, Pourhosein R, Rostami R, et al. Perfectionism and fatigue in multiple sclerosis. *Psychol Health* 2011;26:419–32.
- Skerrett TN, Moss-Morris R. Fatigue and social impairment in multiple sclerosis: the role of patients' cognitive and behavioural responses to their symptoms. *J Psychosom Res* 2006;61:587–93.
- Dures E, Kitchen K, Almeida C, et al. "They didn't tell us, they made us work it out ourselves": patient perspectives of a cognitive-behavioral program for rheumatoid arthritis fatigue. *Arthritis Care Res* 2012;64:494–501.