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Conceptualizing the benefits of a group exercise programme developed for those with chronic fatigue: a mixed methods clinical evaluation

Purpose:

Fatigue is a disabling and prevalent feature of many long-term conditions. Orthostatic dizziness is a commonly experienced by those with fatigue. The purpose was; to evaluate factors contributing to successful delivery of a novel group exercise programme designed for people with chronic fatigue and orthostatic symptoms and identify targets to improve future programme content and delivery.

Research methods:

We used group concept mapping methodology. Participants of the exercise programme- with a long-term physical health condition and chronic fatigue-contributed ideas in response to a focus question. They sorted these ideas into themed piles and rated them for importance and success of the programme delivery. Multidimensional scaling and cluster analysis were applied to the sort data to produce ideas clusters within a concept map. Value ratings were compared to evaluate the success of the programme.

Results:

The resulting concept map depicted seven key themed clusters of ideas: Exercises, Group atmosphere, Physical benefits, Self-management of symptoms, Acceptance and Education. Value plots of the rating data identified important and successful conceptual ideas.

Conclusions:

The concept maps have depicted key concepts relating to the successful delivery of a novel exercise programme for people with fatigue and identified specific targets for future programme enhancements.

Keywords: fatigue; exercise; dizziness; physical therapy; mixed-methods; concept mapping; evaluation; long-term conditions

Running Head: Benefits of a fatigue group exercise programme

Word Count: 5044

#### Introduction

Chronic fatigue has been described as a 'disabling, multifaceted symptom that is highly prevalent and stubbornly persistent' [1]. A significant proportion of GP appointments are attributable to fatigue, which is the primary or secondary reason for attendance in 25% of cases [2]. Chronic fatigue is a symptom which is experienced by people with a range of long-term conditions, including up to 70% of patients with rheumatic diseases [3] and a quarter of long-term cancer survivors [4]. Furthermore, fatigue is a dominant feature for many patients with neurological diseases, with 40% of multiple sclerosis patients and one third of Parkinson's Disease patients reporting it as their worst symptom [5].

Fatigue is of course a prevailing symptom of chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME). The literature suggests that the response of the autonomic nervous system is disrupted in patients with CFS/ME compared with controls, with a proportion of these patients experiencing co-morbid positional tachycardia syndrome [6]. Conversely, many patients with primary positional tachycardia syndrome, experience fatigue which impacts on quality of life [7]. Interestingly, positional tachycardia syndrome is a co-morbid feature of a proportion of patients with joint hypermobility spectrum disorders/Ehlers-Danlos syndrome – hypermobility type [8]. A recent study reported fatigue as being present in 79.5% of people with joint hypermobility spectrum disorders/Ehlers-Danlos syndrome – hypermobility type and is associated with orthostatic dizziness, difficulty participating in personal relationships and community, physical activity levels and patient dissatisfaction with how their condition is managed [9].

In the UK, following the publication of the National Institute for Health and Care Excellence (NICE) Guideline on CFS/ME [10], the Department of Health funded

specialist clinical services for patients with CFS/ME in England. However, an audit of the Newcastle upon Tyne CFS/ME service indicated that 40% of patients referred into that service did not meet the Fukuda diagnostic criteria for CFS/ME, a pre-requisite for non-pharmacological therapies [11].

Following a multi-centred randomised controlled trial of interventions for CFS/ME fatigue, graded exercise therapy was recommended as a treatment [12]. However, there has been much controversy over the reported findings of this study, both from researchers and patient groups [13, 14, 15]. Although this approach has been suggested for CFS/ME fatigue, it is not known whether a graded exercise therapy approach is appropriate for a heterogeneous group of fatigued patients with a range of chronic diseases; particularly those who experience comorbid orthostatic dysregulation and related dizziness.

The Newcastle Clinics for Research & Service in Themed Assessment (CRESTA) Fatigue Clinic was established to offer interdisciplinary care for patients with chronic fatigue and a long-term physical health condition. Following its inception in 2013, we conducted a comprehensive service evaluation to determine priority needs of patients, to determine whether they were being met by the service, and to identify targets for service improvement [16]. This study identified that the clinic supported patients to improve their quality of life in many ways including support with increasing physical activity and exercise without reaching burnout. Future targets for improvement identified through this study included support to help patients overcome the symptom of dizziness and identifying new ways of managing their fatigue.

Within the Newcastle CRESTA fatigue clinic, we developed a group therapeutic postural control exercise programme for fatigued patients identified through physiotherapy assessment as experiencing movement dysfunction and poor postural

control. The intervention accounts for orthostatic problems (such as difficulty in regulating heartrate and blood pressure in response to gravity) that patients may have. All CRESTA fatigue clinic patients who receive physiotherapy within the clinic and live geographically close enough to allow for weekly visits, are invited to attend the group exercise programme. Group sizes are restricted to a maximum of nine patients per programme due to available space and to ensure that patients can receive tailored support.

The aim of this study was to evaluate factors contributing to the successful delivery of the fatigue group exercise programme from the perspectives of service-users and to identify specific targets to improve the content and delivery of future programmes within the service.

#### Content of the intervention

The group exercise programme runs in a block of weekly one hour sessions for 6 weeks. It includes a series of floor and chair-based exercises and progresses to exercises, which are carried out in standing. The sitting and standing ratios increase incrementally over the 6 weeks. Each session ends with a 10-minute meditation. The exercises concentrate on activating deep local muscles to stabilise spinal segmental movement, while the local muscles in conjunction with intra-abdominal pressure, transfer load [17]. Initally, the load is limited to moderated lower and upper limb movement and then progresses to transferring the load between the thoracic cage and pelvis, or vice versa and practiced in various postures. The programme is tailored for each patient and everyone is encouraged to pace themselves. Therefore, patients with more severe presentations and/or orthostatic symptoms, may be encouraged to carry out fewer of the exercises and/or to do them in an adapted, recumbent posture. There are no aerobic exercises included within the programme. The detailed programme is available

upon request from the authors and specific modifications for patients with orthostatic dysfunction can be seen in our previous publication [18]. Occasionally, patients who are more severely affected with fatigue are offered places on subsequent programmes in order to facilitate the gradual increase of their exercise tolerance and capacity over an extended period of time. This results in an overlap of patients with prior experience of the programme interacting with patients who are new to the programme.

#### Aims and objectives

The aim of this study was to evaluate factors contributing to the successful delivery of the fatigue group exercise programme from the perspectives of service-users and to identify specific targets to improve the content and delivery of future programmes within the service.

We used a group concept mapping mixed methods approach to evaluate the group exercise programme [19]. The structured group concept mapping approach allows for the depiction of a concept map, which represents the composite thinking of a group. Priority ratings can be applied to the data to determine key areas of importance and success. In addition, bivariate comparisons can be made across rating criteria to help pinpoint high priority and successful factors as well as priority, less successful factors which are potential targets for future service developments.

This project was registered with the Newcastle upon Tyne Hospitals NHS Foundation Trust as a service evaluation. As such, no research ethics committee permissions were required.

#### **Materials and Methods**

#### Participants and data collection

All patients who had completed the programme and current patients enrolled in the

exercise programme were invited to take part in the group concept mapping evaluation. Patients who had previously taken part in the programme were invited to take part via a postal invitation which contained an explanation of the evaluation, a brainstorming questionnaire, a separate demographic questionnaire and a prepaid return envelope. Current patients of the group exercise programme were invited to take part in the evaluation at the end of a group exercise session by the group facilitator. The brainstorming questionnaire responses were kept separate from the demographic questions to ensure anonymity of the generated ideas. There were three distinct phases to our group concept mapping study.

#### Phase 1: Idea generation and synthesis

All respondents were invited to provide as many single sentence responses as possible to a focus question which asked, "What has the CRESTA Fatigue exercise class done for you?". This process generated a list of statements. The ideas were synthesised by members of the evaluation team (VS, KH, DW, VD). First, statements which had more than one idea within them were split to ensure that each statement contained a single idea. Second, each statement was given a keyword – usually a noun or verb which appeared within the statement and captured its essence. Statements which were allocated similar or identical keywords were considered together and duplicate ideas were removed. The refined final statement list was checked for syntax and grammar before being allocated a unique random number within the Concept Systems Global Max<sup>TM</sup> software.

#### Phase 2: Structuring the ideas

The numbered statements were printed onto individual cards and previous participants of the exercise program were then invited to complete a card sorting

activity. Respondents were each asked to arrange the numbered statements into piles which contained similar meaning statements and they were asked to provide a name for each of their piles. Next, respondents were invited to provide value ratings for each statement by giving a score for both *importance* and *current success* on a *1-5* Likert scale. The instructions for the importance rating were 'rate each statement below on how *important* you think it is by putting a circle around a number'. The number 1 on the rating scale represented 'relatively unimportant' and 5 'extremely important'. The current success rating instructions were 'rate each item according to how *successful* the exercise group is at addressing that need currently'. Number 1 on the scale represented 'Need not being met at all' and 5 'Need is successfully met'. The sorting and rating data were entered into the Concept Systems Global Max<sup>TM</sup> software for analysis.

#### Phase 3: Data analysis and interpretation

The sort data from each participant was arranged within a binary squared similarity matrix and multidimensional scaling applied to this data [19]. Coordinates for each statement were generated and each numbered statement positioned in relation to the others as a numbered point on an *x-y* axis. This point map produced from the data within the binary squared similarity matrix, visually represented how all the participants sorted the statements. Ideas which have been sorted together frequently are located near to each other within the map. Dissimilar ideas (those which have been sorted together less frequently by participants), have greater geographical distance between them.

Multidimensional scaling produces a stress value; an indication of how well the data from the similarity matrix fits with the multidimensional scaling solution in the point map [20]. A stress value below 0.36 is preferable in group concept mapping studies [21] as the resulting map will be readily interpretable [20].

We next applied hierarchical cluster analysis using Ward's method [22] to the point map. This organises the numbered statements into meaningful content within themed clusters [20]. Three members of the evaluation team initially examined as many as 16 clusters and as few as 4 (VS, KH and DW). We considered whether the statements within the cluster fitted the overall theme. If clusters located close to each other contained very similar meaning statements and clusters, we combined them and proceeded to the next iteration. We continued this process until several discrete themed clusters remained, each containing statements which related to the overall cluster theme.

We undertook a cluster label analysis to determine the names of the clusters. The software suggests the top 10 best-fitting names for each cluster using the pile names suggested by participants during the sorting exercise. The evaluation team used the suggested cluster names as guidance, before deciding upon names which best described the content of each cluster [20]. The final cluster solution and cluster names were agreed by all authors and discussed with patients who have attended the group exercise programme.

Importance and success ratings were finally calculated for each cluster. This generates overall ratings for each cluster (by calculating the mean cluster rating scores for each statement within the cluster) as well as individual statement scores. We generated a pattern match (a visual representation of differences between ratings for the clusters) to compare the mean importance and success scores for each of the clusters. In order to compare the importance and success ratings for each statement, we generated a bivariate plot which is demarked by mean cut-off scores for both ratings. Within this plot, statements which were above average for both importance and success, give an indication of priority needs which are being met by the exercise programme. This area of the plot is considered to be the 'go-zone'. These are the ideas deemed by respondents

to be both important and successful. Statements which are above average for importance but below average for success are also demarked in a quadrant of the plot. These statements are considered to be priority needs which are future 'targets for improvement'.

Due to the mixed reports about the benefits of exercise for people with CFS/ME, we conducted subgroup analyses to compare the rating data of those with CFS/ME with the remaining exercise group participants. We generated pattern matches to compare importance and success ratings of this subgroup of patients with those who had primary diagnoses other than CFS/ME. Next, we generated bivariate plots to examine the success scores of the CFS/ME subgroup compared with other participants for any clusters with overall themes conceptually relating to exercise, in order to determine any differences in scores for individual statements within these clusters of interest.

To develop a formal action plan, the results were reviewed and discussed by the evaluation team in collaboration with patients who have accessed the exercise group in order to guide further planning.

#### **Results**

#### Participant characteristics

Of the 59 patients invited to take part in the evaluation, 33 (55%) took part in one or more stage of the group concept mapping exercise. Twenty eight (85%) of the respondents were female. In the non-responder group, 22 exercise group participants were female (85%). Out of the 26 non-responders, 22 were female (85%). An independent t-test revealed no significant differences between the mean age of the responders (45.58 (SD 14.13)) and non-responder (mean=42.19 (SD 12.14)) groups (t(56)=0.99 p=0.327). The primary diagnosis of respondents and non-responders can be

seen in table 1. None of the participants were undertaking regular exercise before starting the exercise group programme. -----Table 1 to go around here-----Twenty patients completed the brainstorming exercise. This activity generated 158 statements, that following the statement reduction process, was reduced to a set of 74 unique ideas. Eighteen patients took part in the card sorting activity and 24 rated the statements (22 rating the statements for importance and 22 rated the statements for current success). The brainstorming activity generated 158 statements, that following the statement reduction process, was reduced to a set of 74 unique ideas. Multidimensional scaling resulted in a point map with a stress value of 0.255. There was consensus on a 7cluster solution which included following themed clusters: Exercises, Class atmosphere, Physical benefits, Self-management of symptoms, Acceptance, Education and Looking forwards. The concept map depicting the themed clusters and location of the statements can be seen in figure 1. The pattern match comparing the average importance and success scores for each themed cluster can be seen in figure 2. -----Figure 1 to go around here----------Figure 2 to go around here-----The numbered statements and their individual importance and success ratings can be seen in table 1 within each themed cluster. The scatterplot comparing importance and success ratings for each numbered statement can be seen in figure 3. The statements falling within the 'go-zone' and 'targets for improvement' quadrants in the scatterplot are identified in table 2. -----Table 2 to go around here-----

-----Figure 3 to go around here-----

#### Exercises (8 statements)

This cluster was rated as being the most important by service-users. Six out of the eight statements within the Exercises cluster fell within the go-zone, indicating that these are important needs which are being successfully met by the group exercise programme. These statements related to knowledge about which exercises to do and how to perform them correctly. Diversity in the types of exercises was also an important factor which was being successfully met by the current programme. The remaining two statements were identified as being targets for improvement. These related to perceived improvement in exercise tolerance and feeling physically better after completion of the programme.

#### Group atmosphere (16 statements)

This was the second most important themed cluster and was rated as being the most successful by respondents. Twelve of the sixteen statements fell within the green gozone area. These included; #19 My needs were recognized, #26 The class was a support for me and #29 The staff are compassionate. No statements in this cluster were identified as being targets for improvement.

#### Physical Benefits (11 statements)

Four statements within this cluster fell within the go-zone. They were: #58 Helped me recognize my poor posture; #14 Knowledge of how to improve core strength; #30 Made me aware of why it is important to exercise and maintain muscles/joints and #35 Made me aware of how exercise can help chronic fatigue. Three targets for improvement were identified in this cluster: #66 It is now easier to do some activities in the home; #57 Helped to improve my symptoms and #18 Helped me to improve my balance.

#### *Self-management of symptoms (7 statements)*

There were two go-zone statements in this cluster which related to patients being provided with appropriate self-management advice. One improvement target was identified: #67 I feel as though I'm being given the right tools to aid my recovery.

#### Acceptance (11 statements)

There were no go-zone statements identified within this cluster. One target for improvement was identified: #69 Improved my attitude towards my fatigue.

#### Education (13 statements)

Several targets for improvement were identified in this cluster: #59 Addressed my symptoms; #34 Helped me to deal with my fatigue better and #71 Helped me devise coping strategies.

#### Looking forward following the programme (8 statements)

We identified one go-zone statement within this cluster and one target for improvement. The priority need which was being successfully met was #74 Helped me feel like I'm not alone with my condition and/or symptoms. The target for improvement was #27 The class confirmed my belief that I can improve some of my symptoms.

#### Subgroup analyses

To determine whether there were any differences in rating scores at cluster level for participants with a primary diagnosis of CFS/ME and group participants with other diagnoses, pattern matches were generated to compare importance and success ratings for each of the themed clusters. These can be seen in figure 4.

-----Figure 4 to go around here-----

Bivariate plots were generated to compare the CFS/ME participants success rating scores for the Exercises and Physical benefits clusters. The go-zones within these plots highlight statements rated as being highly successful by both CFS/ME patients and remaining respondents and can be seen in figure 5. Interestingly, within the Physical benefits cluster, the participants with CFS/ME rated statements #13 Helped my mobility and #22 I have better core strength as having greater success than the non-CFS/ME group. The CFS/ME group rated #2 Helped me with my breathing as lower than the participants with other diagnoses. However, for all other statements, there was a high level of agreement between the two subgroups.

-----Figure 5 to go around here-----

#### **Discussion**

We have conducted a comprehensive evaluation of a novel group exercise programme developed for a heterogeneous group of patients experiencing the debilitating symptom of chronic fatigue. The group concept mapping approach has captured the collective views of patients accessing the programme, conceptualised their ideas within themed clusters in the concept map and added value ratings to both the clusters and the statements within. This has enabled us to identify priority themes and evaluate the success of the programme.

The Exercises cluster was rated as the most important themed cluster. The large proportion of statements within this cluster which fell within the green go-zone area demonstrate that knowing the appropriate exercises to do, and feedback from a clinician that these exercises are being performed correctly is important to patients and a key part of successful programme delivery. The personalised nature means that despite patients having a range of underlying diseases, their individual requirements can still be addressed within a group setting. However, it was also important to patients that they

felt physically better by the end of the programme and they feel that their fitness tolerance is improving. These priorities are not currently being met successfully by the group exercise programme. One possible reason for this is that the exercises focus on postural stability and do not include an aerobic component. A rationale for this group was to address postural control and symptoms of orthostatic intolerance in patients with fatigue. We propose that this approach may provide a valuable foundation to patients prior to embarking on more vigorous, aerobic activity such as walking which requires an upright posture. A recent study has shown that a supervised walking programme decreases fatigue and improves physical fitness in women with primary Sjögren's syndrome [23] and a recent Cochrane review of aerobic exercise training in patients with fibromyalgia concluded that aerobic exercise may improve physical fitness and health related quality of life [24]. We are planning further stepwise development of our clinic model to include other exercise components, particularly aimed at those who are successfully managing their orthostatic symptoms. Further research to determine the effectiveness of postural control and aerobic exercises would be required in a heterogeneous group of patients experiencing chronic fatigue.

Patients appreciated the atmosphere of the group exercise programme. Our results demonstrate the importance of compassionate clinicians who validate and believe their patients symptoms. This supports the findings from our previous service evaluation [16]. Furthermore, patients' have shown that their unique needs are recognised within a group programme and interventions can be tailored within a group setting. Being part of a welcoming small group environment was important to patients. It was important for patients to make connections with others who were experiencing similar difficulties. A recent systematic review of key features and the role of peer support within group self-management interventions for stroke patients has shown that

group interventions offer a way of providing peer to peer support, opportunities for vicarious experiences, social comparison and for increasing motivation [25]. This evaluation has demonstrated that our group exercise programme goes some way to delivering these elements of peer support. As peer support is such an important factor to patients, clinic staff have also supported a group of patients who have completed the programme and wanted to set up their own peer support group within the community.

While patients indicated that they experienced improvement in knowledge about physical benefits through taking part in the group exercise programme, it did not necessarily result in perceived functional improvements such as carrying out activities more easily in the home and improvement in balance. While the group exercise programme forms part of what is offered by the CRESTA fatigue service as a whole, there are many other facets to the service. This finding has indicated the importance of integration of occupational therapy with those who are taking part in the programme to support patients with their functional and participatory goals. We have therefore made further improvements within the service as a result of this finding, including offering follow-up appointments with the occupational therapist to re-address personal self-care, productivity and leisure goals following the completion of the exercise programme.

The central location of the Self-management of symptoms cluster, indicates a conceptual relationship with the clusters surrounding it. Our results indicate that the programme is supporting patients to self-manage their symptoms through the provision of appropriate advice and through having an understanding of why certain symptoms may be exacerbated through doing the exercises. Another example of a physiotherapy exercise programme which includes self-management and active coping strategies within its intervention design is a physiotherapy group programme for osteoarthritis (OA) knee pain. This intervention has demonstrated effective clinical outcomes within

an OA knee pain population [26] and includes some similar intervention components to our group exercise programme for people with chronic fatigue. A target for improvement within the Self-management cluster was providing patients with appropriate tools to aid their recovery (#67). Despite this statement falling just below the current success mean cut-off demarcation line in the bivariate plot, we have improved accessibility to tools we provide in the clinic such as ensuring that our Managing Your Energy booklet [27] is available online. In addition we have produced further specific exercise sheets which are customised for each patient following their 1:1 physiotherapy assessment.

Within the Acceptance cluster, we identified one target for improvement.

Respondents indicated specifically that they would like support to improve their attitude towards their fatigue (#69). Acceptance is a complex process frequently involving an exploration of new identity, re-evaluation of personal goals and life priorities. It is a predictor of emotional stability and fatigue severity in people with CFS/ME [28]. A recent cohort study measuring the effectiveness of a 3.5 week acceptance and commitment therapy intervention with people absent from work with the symptom of chronic fatigue demonstrated significant improvements in quality of life and fatigue and these improvements were associated with a reduction in fear-avoidance cognitions and all-or-nothing thoughts [29]. Patients experiencing all-or-nothing thinking styles or fear avoidance cognitions may therefore benefit from a course of acceptance and commitment therapy [30] as an adjunct to the programme. The exercise group seems to provide an environment in which group members can continue to explore the topic of acceptance, although it is not the primary goal of the programme. Within the clinic we have access to psychological support to explore acceptance further. Future planned

service improvements include group sessions facilitated by a psychologist to explore this topic with patients.

While the Education was seen overall as being a lower priority conceptual theme, there were several improvement targets identified within this cluster. In the light of these results, we have considered how we can offer a psychosocial group programme within the clinic based on the Reducing Arthritis Fatigue by clinical Teams trial [31] manual. This intervention has demonstrated significant improvements in overall fatigue, emotional fatigue, fatigue impact, living with fatigue and self-efficacy, with very high patient satisfaction in patients with rheumatoid arthritis fatigue [32]. Furthermore, it addresses improvement targets identified within the Education cluster.

The lowest priority cluster was Looking forward following the programme. The go-zone statement within this cluster clearly demonstrates that the group exercise programme addresses the feeling of being alone with both a particular condition and the symptom of fatigue. Loneliness is a predictor of fatigue, pain and depression in cancer survivors [33] and is likely to have a negative impact on health [34]. We have demonstrated that a lack of peer support can be targeted within a clinic environment. However, it is not a long-term solution. It is important that patients are able to establish their own support networks within their communities. The independent peer support group established by patients themselves who have been through the programme has made this possible and clinicians within the clinic are able to signpost patients to this group.

The subgroup analyses comparing rating scores for patients with CFS/ME and those with other diagnoses, overall showed a high level of agreement for between these patients and those respondents who had other primary diagnoses. The pattern match for the importance ratings showed that the CFS/ME subgroup rated all themed clusters as

being more important than the remaining participants, with other diagnoses. However, overall, there were few observable differences for success scores between both participant groups. Whilst there is much debate within the literature about exercise for people with CFS/ME, a recent Cochrane Review [35] concludes that patients who are able to attend a clinic, with less severe presentations of CFS/ME, may generally benefit and feel less fatigued following therapy and that there is no evidence to suggest that exercise therapy may worsen outcomes. Furthermore, a recent qualitative study investigating guided graded exercise self-help [36] demonstrated that guidance from skilled health professionals with an understanding of CFS/ME is important and support through the 'indeterminate phase' – a stage experienced by some people early on in the programme where an initial worsening of symptoms may be experienced.

Considering the results as a whole, the programme seems to support participants' self-efficacy and resilience. People with long-term conditions may experience social stigma particularly when there are no obvious distinguishing features. Fatigue is often an invisible symptom and yet the impact on patients' lives can be huge [37]. Our results indicate that the provision of specialist, tailored support to target fatigue and orthostatic symptoms within a supportive, compassionate group environment supports patients' knowledge of self-management strategies and offers opportunity to access support from peers. This study has shown that the components, which patients appreciate within a fatigue exercise programme, are varied, but include physical factors including appropriate exercises and physical benefits, as well as psychological and social factors including the friendly and accepting atmosphere and advice to support self-management. Whilst this programme seemed to suit a heterogeneous group of patients with various clinical diagnoses within an outpatient clinic setting - including those with CFS/ME - similar exercise programmes may be of

relevance to people with fatigue in wider practice. For example, there is potential for tailoring the programme delivery within primary care or within local community settings. Whilst the effectiveness of fatigue exercise programmes have been demonstrated within local communities for specific patient groups [38, 39], our study has demonstrated the successful delivery of a programme delivered to a heterogenous group of patients with the common symptom of fatigue. Further research should be conducted to investigate the efficacy of similar programmes to mixed patient groups within community and primary care settings.

#### Limitations of this study

This was a service evaluation, not an effectiveness study. The study included a heterogeneous group of participants with various clinical presentations. The largest single group of participants who took part in the study had CFS/ME. We therefore performed subgroup analyses on these participants to determine any differences in success scores from these patients compared with those participants with other diagnoses. A future evaluation including larger subgroups of participants with particular clinical presentations would be worthwhile. A further limitation was that we did not collect data from participants on the duration of their fatigue symptoms. A future evaluation may detect differences in success scores of those with a relatively short fatigue duration and those who had experienced chronic fatigue for many years. Despite these limitations, the evaluation has highlighted some improvement targets, which can be made within the group exercise programme as well as within the wider service and the community. Additional studies are required to determine the effectiveness of these interventions.

#### **Conclusion**

We have used a systematic approach asking people attending our fatigue clinic their views of our group exercise group and their priorities for this component of our clinic model going forward. Our findings highlight a service that meets the needs of this group and their priorities. It also raises other areas where on-going patient priorities need to be incorporated into our clinic in order to support our patients.

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Table 1. Contingency table demonstrating the primary diagnosis of all patients in the group exercise programme, including both responders and non-responders in the clinical evaluation

	Diagnosis		
	Participants (n)	Non-participant (n)	Total
CFS/ME	10	6	16
Connective Tissue Disease	0	1	1
EDS/Joint hypermobility	3	4	7
Fibromyalgia	0	1	1
Inflammatory arthritis	0	3	3
Kidney Disease	1	0	1
Liver disease/transplant	2	1	3
Multifactorial diagnoses	2	2	4
Neurological disorder	2	2	4
Postural orthostatic	3	3	6
tachycardia Syndrome			
Primary Sjögren's	10	2	12
syndrome			
Vasovagal syncope	0	1	1
Total	33	26	59

Table 2. Mean importance and success ratings for the clusters and for each numbered statement within each cluster

		Importance (1-5)	Current Success (1-5)
Exerc	ises	4.45	4.27
38*	I understand which exercises will help me	4.64	4.48
40*	Provided with me with appropriate exercises to do	4.59	4.36
37*	Knowing that you are doing the exercises correctly	4.50	4.64
72*	Helped me to use my muscles correctly	4.43	4.23
60*	Showed me how to modify the exercises to make them easier/more difficult as appropriate	4.41	4.41
54*	There was a diversity of exercises in the class	4.36	4.36
$65^{\dagger}$	Helped me to improve my exercise tolerance	4.36	3.77
39 <sup>†</sup>	I felt physically better after completing the course	4.27	3.91
Group	o atmosphere	4.44	4.47
7*	The small classes provided a personal touch	4.82	4.77
8*	Nice and friendly atmosphere	4.82	4.82
10*	My symptoms were understood in the class	4.82	4.55
52*	The staff were supportive	4.77	4.86
29*	Staff are compassionate	4.73	4.91
45*	During the class I was regularly monitored by staff	4.59	4.77
48*	Being with people with similar issues was supportive and reassuring	4.59	4.23
19*	My needs were recognised	4.57	4.50
51*	I feel comfortable in the group	4.55	4.73
17*	I felt welcomed into the group	4.50	4.82
26*	The class was a support for me	4.45	4.59
49*	An opportunity to meet people experiencing similar problems	4.45	4.41
25	The class is fun and enjoyable	4.23	4.50
6	The class has good facilities (room, mats etc.)	4.09	4.09
64	The class was a social opportunity	3.82	3.82
12	Has helped me to build a support network	3.23	3.18
Physic	cal benefits	4.30	4.05
58*	Helped me recognize my poor posture	4.55	4.45
$66^{\dagger}$	It is now easier to do some activities in the home	4.55	3.68
14*	Knowledge of how to improve core strength	4.50	4.41
30*	Made me aware of why it is important to exercise and maintain muscles/joints	4.45	4.45
35*	Made me aware of how exercise can help chronic fatigue	4.45	4.32
$57^{\dagger}$	Helped to improve my symptoms	4.36	3.81
$18^{\dagger}$	Helped me to improve my balance	4.29	3.73

Г			
31	Helped me to improve my muscle strength	4.18	4.14
13	Helped with my mobility	4.09	3.73
22	I have better core strength	4.05	4.00
2	Helped me with my breathing	3.81	3.81
Self-m	nanagement of symptoms	4.25	4.06
68*	Provided me with appropriate advice	4.62	4.55
36*	I was provided with appropriate advice to help me self-manage	4.36	4.23
67 <sup>†</sup>	I feel as though I'm being given the right tools to aid my recovery	4.33	4.09
41	I better understand which symptoms I may experience during each exercise	4.23	4.45
46	Addressed my fatigue	4.23	3.82
5	Provided me with the correct tools to aid my recovery	4.18	3.95
20	I was signposted to other sources of support (e.g. organisations/support groups)	3.77	3.36
Accep	tance	4.09	3.80
$69^{\dagger}$	Improved my attitude towards my fatigue	4.29	3.81
42	Provided me with hope	4.23	3.95
70	Helped me accept my situation	4.19	3.77
1	Helped me to accept my symptoms	4.18	3.86
9	Helped me accept my limitations	4.18	3.50
16	I understand myself better	4.14	4.27
53	Helped me not to be too hard on myself	4.14	4.05
3	Helped me to enjoy life at a slower rate.	4.00	3.18
43	Has helped me value what I am capable of	3.95	3.95
63	Improved my confidence to express myself	3.91	3.59
56	Shown me that asking for help is not a weakness but a step forward	3.82	3.82
Educa	tion	4.05	3.93
59 <sup>†</sup>	Addressed my symptoms	4.36	4.05
$34^{\dagger}$	Helped me to deal with my fatigue better	4.32	3.82
$71^{\dagger}$	Helped me devise coping strategies	4.29	3.95
21	Given me a foundation from which I can make further progress	4.24	4.36
61	Helped me to monitor my own progress	4.18	4.14
24	Helped me understand the science behind my symptoms	4.14	4.09
23	The meditation helped me to relax	4.09	4.32
32	Helped me understand my condition	4.09	3.95
33	Recognition of the illness process	4.05	3.91
55	Provided me with tools for relapse plan	3.95	3.60
11	Helped me to structure rest breaks/time-outs in my day	3.86	3.95

47	Educated about preventing complications	3.86	3.82	
44	Helped me to educate my employer about my condition/symptoms	3.18	3.12	
Lookii	Looking forward following the programme 4.07 4.05			
74*	Helped me feel like I'm not alone with my condition and/or symptoms	4.81	4.45	
27 <sup>†</sup>	The class confirmed my belief that I can improve some of my symptoms	4.36	4.09	
15	I have been inspired by staff	4.14	4.32	
73	Identified problems and signposted me to the correct professionals	4.00	3.67	
28	The class has given me a purpose	3.95	4.00	
50	Recognised other conditions	3.91	4.27	
62	Attending the class changed some of my preconceived ideas	3.81	3.95	
4	Î have been inspired by others group members	3.55	3.62	
*Go-zone statement †Improvement target statement				

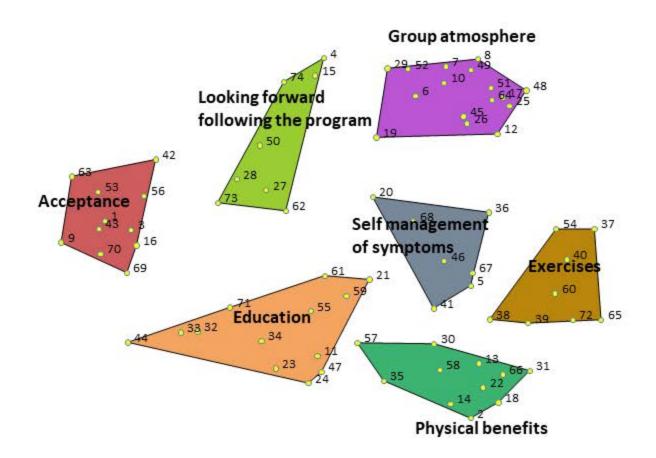
Figure 1. Concept map depicting statements as numbered points within the themed clusters

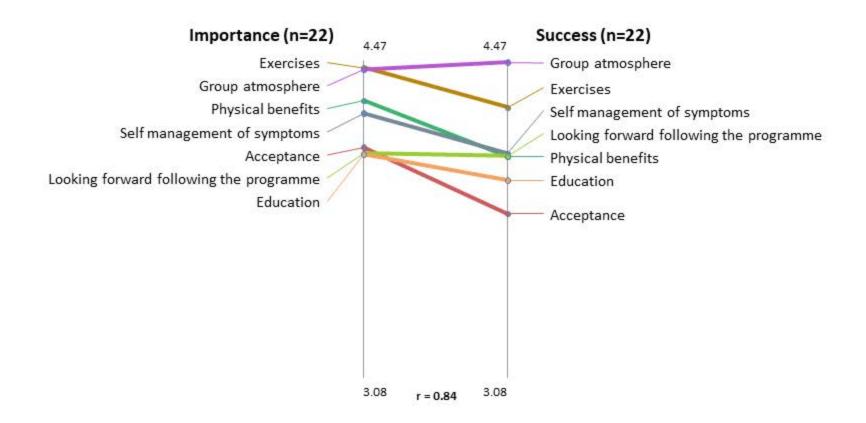
Figure 2. Pattern match depicting the mean importance and success rating scores for each cluster

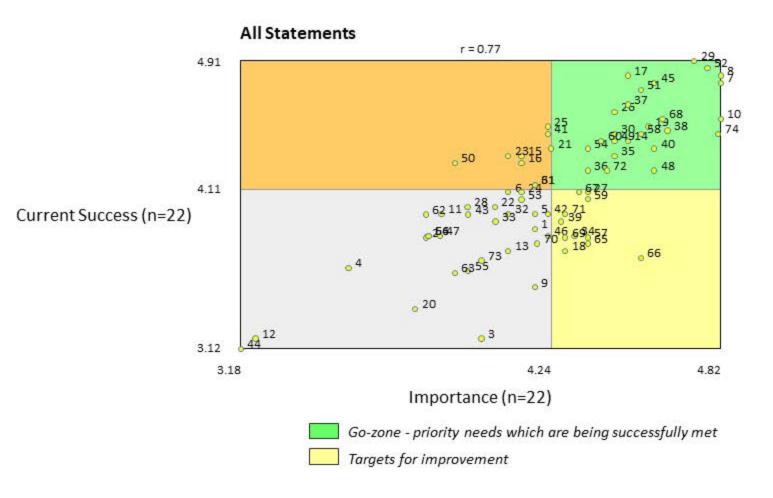
Figure 3. Scatterplot demonstrating importance and success scores for all statements with go-zone statements and targets for improvement statements demarked

Figure 4. Pattern matches comparing importance and success scores for the CFS/ME subgroup with the participants who had other primary diagnoses

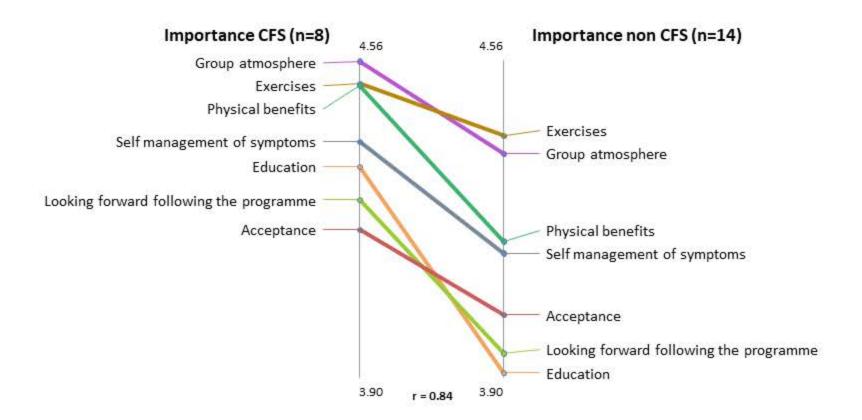
Figure 5. Scatterplots comparing success rating scores of CFS/ME participants with remaining respondents for statements within two selected clusters



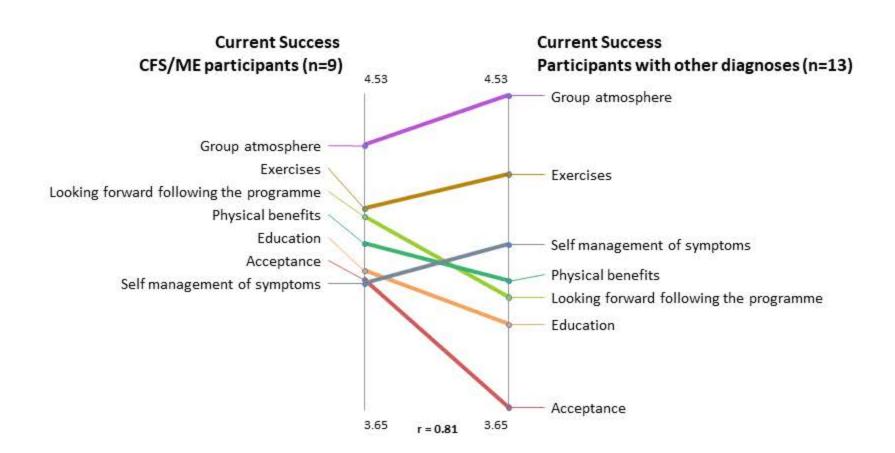




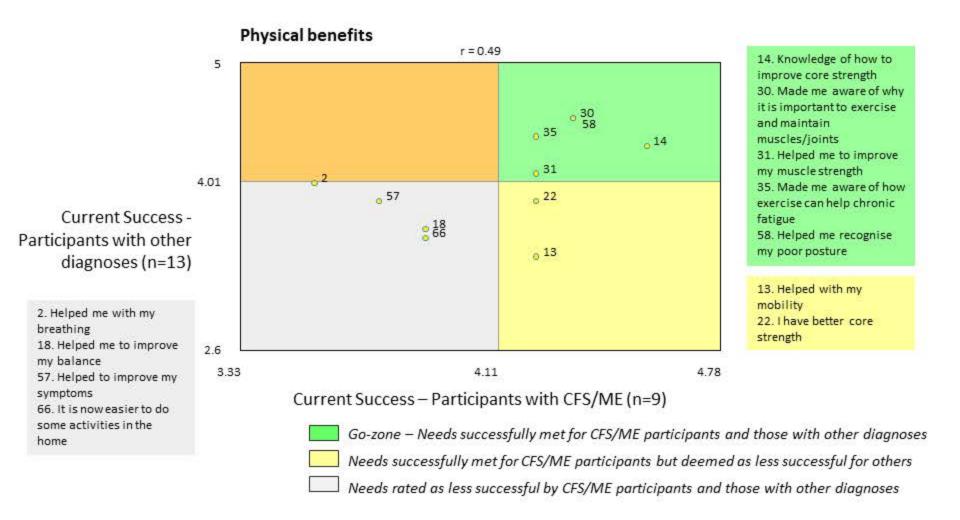
### Pattern match comparing importance ratings of participants with CFS/ME and those with other diagnoses



## Pattern match comparing success ratings of participants with CFS/ME and those with other diagnoses



# Bivariate plot comparing success rating scores of CFS/ME participants and those with other diagnoses for the Physical benefits cluster



## Bivariate plot comparing success rating scores of CFS/ME participants and those with other diagnoses for the Exercises cluster

