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#### Intervention

# Learning to cope with chronic illness. Efficacy of a multi-component treatment for people with chronic fatigue syndrome

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#### ABSTRACT

*Objective:* The aim of this study was to determine the efficacy of an out-patient, multi-component programme developed for patients with chronic fatigue syndrome (CFS). *Methods:* Twenty-two patients were assessed before and after six months of treatment. Findings were

compared with 22 individuals on the waiting list. The programme offered medical care as well as information and counselling to help patients to understand, accept and cope with their illness. *Results:* At six months, there were significant differences between the groups for fatigue, self-efficacy and anxiety. Overall, 82% of the treated patients reported feeling better and 23% had improved to such a degree that they were discharged from the clinic. The gains were maintained at twelve months. *Conclusion:* This programme was found to be both helpful and acceptable and may provide a useful first-

line intervention for many patients with CFS. *Practice implications:* Short, pragmatic programmes may be as effective as cognitive-behaviour therapy.

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#### 1. Introduction

Chronic fatigue syndrome (CFS) is a disabling illness characterised by profound fatigue and other symptoms, including musculoskeletal pain, sleep disturbance, impaired concentration and headaches [1]. Although many cases appear to follow an acute infective illness, research has yet to clarify the role of pathogens in the perpetuation of symptoms [2,3]. The lack of knowledge regarding aetiology and the absence of effective pharmacological treatments have led to the development of programmes aimed primarily at enhancing coping, limiting functional impairment and reducing emotional distress.

Two of the most helpful interventions which have been studied in controlled trials are cognitive-behaviour therapy (CBT) and graded activity/exercise [4,5]. However, while the research has shown that these interventions often result in significant overall reductions in fatigue, improvements have tended to be modest and a proportion of patients do not benefit [4–7]. One reason for the moderate effects may be the heterogeneity of the population with CFS [3]. Indeed, the current working case definition for CFS has been shown to select a number of distinct subtypes which differ from each other not only in terms of the type and severity of symptoms, but also appear to be associated with different

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immunological and other pathophysiological abnormalities [3,8–11]. It has been suggested that the more structured CBT programmes described in the literature may not meet the different challenges and needs of all individuals with CFS, and that more flexible, tailor-made interventions could offer an effective alternative [12].

Most of the multi-component programmes which have been evaluated incorporate aspects of CBT and although the preliminary results have been encouraging, the majority offer few strategies for patients with neurological and immunological abnormalities, and those already operating at their maximum level of functioning [13–16]. There are several notable exceptions. For example, Jason et al. compared four interventions, including CBT, relaxation, anaerobic activity and a programme providing strategies to reduce stress and balance rest and activity [17]. It was found that the latter yielded the greatest overall improvements although the changes were modest and there were no additional gains at follow-up.

Another alternative to the CBT-based interventions is a programme devised by Ho-Yen [18]. Although this includes elements of CBT, e.g. keeping a diary to identify links between activities, stress and symptoms, it does not assume that the illness is perpetuated by phobic avoidance behaviour and physical deconditioning [19,20]. Accordingly, patients do not have to follow pre-determined schedules to improve fitness but are advised to rest both when they begin to feel unwell and for set periods during the day. This approach, aimed at reducing fatigue and avoiding overexertion, is therefore appropriate for the more

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active patient as well as individuals with a concurrent infection who may have an adverse reaction to graded exercise [21-24]. The additional periods of rest also provide patients with time to relax and unwind. This is considered to be particularly important in CFS as emotional stress has been linked with activation of the hypothalamic-pituitary-adrenal axis, and a number of immunological abnormalities which may exacerbate symptoms and undermine recovery [17,20]. Other components of the programme are largely psycho-educative and aimed at increasing the individual's resources to deal with the illness and its psychosocial sequelae. According to Lazarus's theory of Stress and Coping, the condition is therefore more likely to be appraised as manageable, thus avoiding the physiological changes associated with threatening cognitions which can have a negative impact on adaptation, well-being and functioning [25, p. 209]. Moreover, the programme should increase perceived self-efficacy, noted in previous studies as a predictor of improvement over time and in patients treated with CBT [26,27].

Similar interventions which have combined medical care with a psycho-educative approach have been found to be beneficial in other chronically ill groups (e.g. [28,29]), but to our knowledge, this is the first evaluation of such a programme in patients with CFS.

This pilot study was designed to determine the effectiveness of the programme for patients with CFS and to ascertain if the evidence justified a larger scale evaluation.

#### 2. Methods

#### 2.1. Participants and design

Approval was obtained from the Highland Health Board Ethical Committee and conducted in accordance with universal ethical principles. The treatment group comprised 22 people assessed before and six months after starting the programme. The results were compared with those of 22 people on the waiting list. All fulfilled the 'Oxford' research criteria for CFS [30] and clinical criteria formulated by Ho-Yen [31]. None of the patients had a concurrent condition which could have had a significant influence on the assessment of outcome. Further socio-demographic and illness-related information can be found in Table 1. Participants were not paid for their participation.

The design was quasi-experimental, which was chosen because at the time of the study, the delay between acceptance on the waiting list and the first consultation was about seven months. This was sufficient to carry out a before/after assessment in the treatment groups and two assessments of the untreated controls during the same time frame. An alternative design using randomised groups was rejected because this would have required half the patients to spend a further six months without diagnosis and treatment, which was considered inappropriate given the disabling nature of the illness [32].

#### 2.2. Procedure

Patients with a provisional diagnosis of CFS who were referred to a specialist in the condition at Raigmore Hospital, Inverness, UK were sent a letter inviting them to participate in this study. The patients already on the waiting list at the start of the study were sent their first set of questionnaires two weeks prior to their first appointment when the consultant checked the diagnosis and began treatment (T1). A second set was sent five to six months later, prior to their third appointment (T2). Those who joined the list after the start of the study became waiting list controls (WLC). They were sent the first set of questionnaires immediately following receipt of the consent form (T1) and

#### Table 1

Socio-demographic and illness-related information for the treatment group and waiting list controls.

Characteristics	Treatment § N = 22	WL N =	C group 22		
	Mean	(SD)	Me	an	(SD)
Age (years)	39.6	(13.4)	37.	7	(14.4)
Illness duration (years) <sup>a</sup>	4.93	(3.6)	2.	92	(2.3)
		Ν	%	Ν	%
Female		16	73	13	59
Marital status Single Married/cohabiting Separated/divorced		5 15 2	23 68 9	7 13 2	32 59 9
Education completed Secondary school College/university Did not complete		11 2 4	50 9 18	13 2 5	59 9 23
Employed fulltime Changed job/reduced hours o Disability benefits On medication	2 18 3 10	9 86 14 45.5	0 18 5 12	0 95 24 54.5	

<sup>a</sup> *Notes*: significant difference between the groups, p < 0.05.

<sup>b</sup> Treatment group: N = 21, WLC: N = 19.

completed the second set just prior to their first consultation, six months later (T2). The same consultant diagnosed and treated all the patients using the same protocol but did not see the questionnaires [18].

Three of the 25 patients in the treatment group did not fulfil the diagnostic criteria when assessed at T1 and were therefore excluded from statistical analysis. Out of the 27 WLC, two did not fulfil the inclusion criteria when assessed and one chose to begin a different treatment elsewhere. The remaining 24 were diagnosed with CFS but two patients sent incomplete data at T2 and it was not possible to obtain the missing information before their first treatment session. Consequently, their data were also excluded from the analysis.

#### 2.3. Treatment programme

The first consultation lasted about one hour during which the consultant assessed the patient and explained the programme. At the subsequent bi-monthly consultations, the patient's progress was checked and specific problems discussed. Briefly, the programme consists of symptomatic treatment where appropriate plus:

- 1. Diagnosis and information: Patients are informed about the current views on aetiology including the possible effects of ongoing disease, and the influence of other relevant variables, notably 'stress'. This allows the patient to accept their circumstances and improves their understanding of symptoms.
- 2. Diary: This is used to provide a daily assessment of the illness, rated on a visual analogue scale from 0 (severe symptoms, all day in bed) to 100 (complete health). Patients are also required to record the hours spent on activities, sleep and relaxation, plus any problems encountered. This information allows both the patient and consultant to monitor the condition and identify variables which trigger exacerbations.
- 3. Advice about activity management: The programme promotes a combination of pacing, i.e. stopping activities at the onset of fatigue, and pre-emptive rest, i.e. additional periods to conserve

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energy and relax. Gradual increases in activity are permitted when the patient has scored 8/10 in their diary for three weeks.

- 4. Additional advice on limiting distress and increasing energy: This focuses on improving sleep and dealing with challenging relationships.
- 5. Miscellaneous: Other advice covers diet, dealing with irritable bowel syndrome and issues related to employment. More detailed information can be found in Ho-Yen [18].

#### 2.4. Measures

#### 2.4.1. The Profile of Fatigue-Related Symptoms (PFRS)

This 54-item measure developed by Ray et al. [33] assesses the pattern and severity of a number of symptoms commonly reported by patients with chronic fatigue syndromes. Respondents rate the extent to which they experienced symptoms during the past week on a 7-point scale from 0 ('not at all') to 6 ('extremely'). The measure consists of 4 subscales: emotional distress, cognitive difficulty, fatigue, and somatic symptoms. In this study, we will not report the scores for emotional distress as the HADS allowed a more meaningful comparison with other samples.

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

This self-rating scale was specifically designed to assess anxiety and depression in people with medical conditions [34,35]. It has two subscales, anxiety and depression, each with 7 items rated from 0 to 3. The total subscale scores range from 0 to 21. Scores from 0 to 7 indicate normal levels of anxiety and depression, scores of 8 or 9 are regarded as indicating possible (borderline) cases of clinical disorder while scores of 11 or above are considered to reflect probable cases of morbidity.

#### 2.4.3. Functional Impairment Scale

This measure consists of four visual analogue scales covering the ability to work and manage the home, as well as the ability to take part in social and private leisure activities [36]. Participants are asked how much their condition has affected each of the designated areas, with ratings ranging from 0 ('not at all') to 8 ('very severe'). The scores are summed and treated as a single variable. This scale has also been used in other studies on CFS (e.g. [37,38]).

#### 2.4.4. Self-efficacy Scale

This measure comprised a modified version of the Self-Efficacy Other Symptoms subscale [39]. Patients were asked to rate their confidence regarding their ability to control their illness on a scale ranging from 10 ('very uncertain') to 100 ('very certain'). The score was the mean for all six items. Since this measure was originally devised for patients with arthritis, references to 'arthritis' were changed to 'fatigue' or 'illness' depending on the context. Furthermore, in one question, a reference to 'feeling blue' was changed to 'feeling down'. Cronbach's  $\alpha$  for this adapted scale was .83.

#### 2.4.5. Other information

At baseline, participants were asked for socio-demographic information and details about the duration and severity of illness.

#### 2.5. Second assessment (T2)

At the second assessment, patients were again asked to fill in the PFRS, Self-Efficacy subscale, HADS and Functional Impairment Scale. In addition, there were questions to determine if the patients had begun any new treatments since the last assessment, and if there had been any change in their state of health. There was also an open-ended question asking patients who had an additional treatment to indicate if any were helpful.

#### 2.6. Statistical analysis

In order to analyse the differences between the treatment and WLC groups, we carried out a series of Analyses of Variance for all outcome measures at T2, while covarying baseline scores. Although the duration of illness differed significantly between the groups (t = 2.22, df = 42, p = .032), this variable did not correlate with the outcome measures at baseline and T2. Accordingly, it was not considered necessary to include duration as an additional covariate. Missing values were randomly spread and dealt with by inserting the mean of the group for the variable in question into the dataset. All statistical analyses were performed using SPSS version 15.

#### 3. Results

#### 3.1. Effect on outcome measures

As Table 2 shows, the means for the treated group at T2 showed improvements on all measures. Analysis using ANCOVA indicated that the differences between the groups at T2 were significant only for fatigue, self-efficacy, and anxiety. In terms of effect size, the programme had a moderate impact on all symptom measures, except for fatigue, where the effect size was large (Cohen's d = .83).

Examining the HADS scores at T1 for caseness revealed that nearly half of the patients in both groups recorded scores above the cut-off point for possible clinical anxiety and depression. After six months, there was a small reduction in the number of cases of possible anxiety and depression among the treatment group but not among the controls. With regard to those with probable morbidity (scores  $\geq$  11), there was a notable fall in the number of patients with anxiety, from 36% at T1 to 14% at T2, while the percentage of those with depression fell from 23% at T1 to 14% at

#### Table 2

Comparison of the mean scores (+SD) from the treatment group and waiting list controls.

Measures	T1 scores				T2 scores			ANCOVA				
	WLC		Treatment		WLC		Treatment		F	df	р	d
	M	SD	М	SD	M	SD	М	SD				
Fatigue	4.20	1.13	3.50	1.57	3.84	1.40	2.68	1.41	4.22	1,41	.04	.83
Cognitive difficulty	3.06	1.44	2.53	1.33	2.97	1.51	2.28	1.42	2.65	1,41	.11	.47
Somatic symptoms	2.29	1.04	1.94	1.31	2.27	1.06	1.54	1.15	3.78	1,41	.06	.66
Functional impairment	22.91	4.73	22.81	4.63	22.73	5.71	20.86	6.09	1.43	1,41	.24	.32
Self-efficacy	47.22	15.81	47.05	17.54	50.20	17.87	62.14	14.20	6.88	1,41	.01	.74
Anxiety	8.81	3.90	8.77	4.99	8.73	3.93	7.14	3.86	4.66	1,41	.04	.41
Depression	9.59	4.08	7.95	3.84	9.05	3.62	6.59	4.13	2.24	1,41	.13	.63

Notes: WLC: waiting list controls. T2 scores were collected six months after T1. d: Cohen's d was calculated using post-treatment means and SD.

T2. The difference between the groups in the number of cases with probable depression at T2 was significant,  $\chi^2 = 5.1$ , p = .02.

#### 3.2. The patients' views of the programme and clinical outcome

Asked about the changes in their condition during the six months between T1 and T2, 18 out of 22 (82%) of the treatment group rated themselves as 'better', two (9%) regarded themselves as unchanged and two (9%) felt worse. At T2, five (23%) had improved to such an extent that further treatment was thought unnecessary and they were discharged. In contrast, 11 (50%) of the controls felt better overall, 7 (32%) perceived no change and 4 (18%) were worse or much worse.

#### 3.3. Follow-up (T3)

Information was collected five to six months after T2 when the treatment group had been on the programme for approximately one year. As NHS regulations at the time did not permit contact with patients who had been discharged, our aims at T3 were to follow the progress of the individuals who had continued to receive treatment, and to ask the patients for their views of the intervention.

Data were obtained from 19 patients in the treatment group, which included two of the five who had been discharged but who had completed the third questionnaire before we were made aware of the restrictions.

ANCOVAs were carried out on the scores from the treatment group for T2 and T3 using data for T1 as the covariate. There were no significant differences for scores for fatigue ( $F_{1.17}$  = .80, p = .38) self-efficacy ( $F_{1,17} = .05$ , p = .83) or anxiety ( $F_{1,17} = .36$ , p = .55). Thus the improvements identified at T2 were maintained at T3 but additional gains were minimal. Asked for their own assessment of their illness, 12 (63%) of the treatment group noted that they were either 'better' or 'much better' compared to T2. Six (32%) reported no change, and just one person rated their overall condition as worse. Although many patients reported trying other therapies during the course of the programme, none of them attributed their improvement to these treatments when assessed at T3. The commonest reasons given by the treatment group for their improved health included accepting the illness, rest, pacing, the support and care of the doctor, avoiding stress and family support. However, three patients described the recommended periods of rest as "boring", "isolating" and "depressing", and claimed that this had made them feel worse.

#### 4. Discussion and conclusion

#### 4.1. Discussion

The main aim of this study was to evaluate a pragmatic, physician-led, multi-component programme for CFS. After six months, the results showed greater improvements in the treated patients on all measures, and significant differences between the treatment group and controls for fatigue, self-efficacy and anxiety. Indeed, after only three sessions lasting less than two hours in total, 82% of the treated patients rated themselves as 'better' and 23% had improved to such a degree that they were discharged. Moreover, there was a 35% reduction in average fatigue and the number of patients with mild fatigue, defined as a score of 2 or less on the PFRS subscale, increased from 24% at T1 to 41% at T2. These findings suggest that this treatment programme had a moderate but clinically meaningful effect on three of the seven measures examined.

A detailed comparison with other controlled trials is difficult given the differences in samples, design, setting and assessment of outcome. However, it is of interest that where effect size is calculated using Cohen's *d*, the evidence supports the results from Jason et al., that some programmes which are not based on the CBT model may be just as effective as those that are [4,6,17,40]. For example, Nezu et al. [41] analysed the data from the one of the most successful CBT trials [37] and reported moderate effect sizes for physical symptoms (d = .46) and psychological distress (d = .49). These findings are consistent with those of Malouff et al. [7] whose calculations were based on data from 13 studies evaluating CBT and/or graded exercise (d = .48). In our study, treatment had a moderate effect on somatic symptoms and emotional distress, but a larger effect was found for fatigue (d = .83).

Although the effect size statistics suggest equivalent outcomes, it should be noted that the patients on our programme were seen less often and for a shorter period of time than the participants in other trials [5,18,37]. For instance, Deale et al. reported data on 27 patients who completed 13 sessions of CBT with a mean therapist time per patient of 15 h [37]. At six months, 70% of the CBT group rated themselves as 'better' or 'much better', compared to 82% in this programme. Moreover, there were significant differences between the treated group and controls for fatigue and functional impairment, but not for depression, emotional distress and physical functioning. Thus, as in this and other studies on CFS, the treatment was not uniformly efficacious [7].

Possible reasons for the lack of improvement in functional impairment scores in our sample include the effects of emotional distress and the duration of pre-emptive rest. For example, the results from the HADS suggest that referral to a therapist for more specialised treatment might have benefited some of the participants. The time with the consultant might also have been too short to permit the patients to express and process their emotions, identified as a key predictor of positive outcomes following CBT and counselling [42]. However, other programmes are not necessarily more effective in dealing with psychological symptoms. Indeed, the means of the treatment group at T2 were lower than those of patients evaluated by Ridsdale et al. after CBT and counselling [43]. Likewise, the mean anxiety score at T2 was similar to those recorded following a programme emphasising graded exercise [44].

The second factor which may have affected functional impairment scores is the programme's advice on rest. Ho-Yen advocates both recuperative rest, a response to symptoms and aimed at avoiding the exacerbations triggered by over-exertion, and pre-emptive rest, aimed at conserving energy and promoting recovery [18,45]. The feedback indicated that patients who felt relatively well during the periods of pre-emptive rest found this aspect of the programme particularly challenging. Indeed, some noted that the length of time they were advised to rest led to feelings of boredom, isolation and depression. The additional inactivity could be one reason why the functional impairment scores did not match the reductions in fatigue and somatic symptoms at T2. The programme now limits these periods to 30 min, two to four times a day.

Another variable which showed little improvement was cognitive difficulties. As noted by Lazarus [25] and Thomas et al. [46], deficits in attention, memory and concentration could have an adverse effect on the appraisal of stressors and the processing of information, thus adversely affecting both adaptation and mood. Although cognitive symptoms have been implicated as a predictor of functional impairment by others (e.g. [38,47]), few rehabilitation programmes have evaluated strategies to alleviate or compensate for the deficits [46]. Based on the available evidence, additional interventions focused on reducing cognitive symptoms may improve outcome.

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Despite the lack of therapist time, most patients found the programme helpful. It also increased perceived self-efficacy, a factor linked to improvement in other studies [26,27]. Although the drop-out rate (2%) was extremely low compared to the rates reported in reviews of CBT trials (means 16–20.6%) [5,7], some of the participants were unhappy with specific aspects of the treatment. These and the limited improvement in emotional distress indicate that the programme was not flexible enough to respond to specific needs and circumstances, and we therefore concur with others that patients with CFS may benefit from multi-disciplinary interventions offering a wider range of therapeutic options [3,40,46].

This study has a number of limitations which must be considered when interpreting the data. These include the small sample size which precluded a more comprehensive analysis of the results such as a comparison of subsets. A larger trial of the updated programme may also help to address some of the issues raised in this study, notably the effects of reducing the periods of pre-emptive rest and the inclusion of additional interventions for those who require them. A further limitation is that participants were not randomly allocated and the groups differed in terms of the duration of illness. However, as the latter was not significantly correlated with any of the variables of interest, this was not considered a problem. Also, despite lack of randomisation, there were no significant differences found on any of the key measures at T1. Finally, we were denied access to recovered patients at T3. The loss of their data means that the outcomes reported are likely to be an underestimate of the actual effectiveness of the programme.

Despite the limitations, the findings of this pilot study suggest that this programme could provide the basis for a multidisciplinary, multi-component approach to CFS. Indeed, the marked improvements recorded by a quarter of the patients indicate that longer and more intensive interventions are not always required. The fact that all the patients were assessed and treated by the same individual using his own protocol avoided the potential inconsistencies introduced by different therapists, different interpretations of the diagnostic criteria and confounding caused by a lack of fidelity to the prescribed manual [5]. A further strength is that the programme was tested in an outpatient, hospital setting, so the findings are likely to be realistic and replicable in routine clinical practice [6,48]. However, while the results seem to justify a larger trial, we believe that such a study should include the stratification of patients (e.g. post-viral versus gradual onset, high versus low functioning), as well as objective measures of activity and immune status, and a more detailed assessment of cognitive impairment.

#### 4.2. Conclusion

This study shows that a pragmatic, out-patient programme providing symptomatic treatment, practical advice and emotional support can have a positive impact on the severity of fatigue, anxiety and self-efficacy. Although improvements were generally modest, the low attrition rate and the positive feedback indicated that this is an acceptable as well as helpful intervention.

#### 4.3. Practice implications

This programme offers health care providers treating CFS an additional therapeutic option. It provides an alternative to graded activity-based programmes for individuals operating at their maximum level of functioning and those with no or little evidence of phobic avoidance. However, therapists need to develop more effective strategies to reduce cognitive deficits as this aspect of the illness may increase perceived disability and undermine adjustment.

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