Is chronic fatigue syndrome treatable in an NHS environment?

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Abstract

The combined approach of graded activity and cognitive behaviour therapy in the treatment and management of chronic fatigue syndrome within an inpatient NHS neurology ward is discussed. A retrospective medical audit of 28 patients indicated that 57% had an increased activity level six months following discharge. Controlled clinical studies are required to examine the benefit and effect of the combined treatment approach discussed.

Introduction

Chronic fatigue syndrome (CFS), postviral fatigue syndrome and myalgic encephalomyelitis (ME) are names that have been used to describe the same syndrome1. The consensus is that chronic fatigue syndrome is the most appropriate title,2 as it does not presuppose a specific cause and identifies the most prominent feature - fatigue. Information concerning prevalence and the natural history of the syndrome is relatively scarce. It has been suggested that the overall prevalence in the UK is 150 000 cases with a 2:11 predominance of females compared to males.3 The main complaint is persistent fatigue, which differs from normal tiredness as it is usually severe and disabling, affecting physical and mental functioning, and follows minimal effort.1,4,5

The advice given to patients can be misleading. Patients are often told to rest until symptoms subside or to learn to live within their limits and modify their lifestyle.4,6,7 Established treatment approaches are limited.1,4 In a recent review of CFS8 only six out of 75 chapters were devoted to treatment, all of which consisted of studies for immunological therapeutic agents. Patients find it difficult to come to terms with the often prolonged, fluctuating and unpredictable natural history of this disorder and the conflicting professional advice received.1

This paper describes a treatment approach used within an NHS neurology unit. The aim of the treatment approach is to enable the patient to improve daily activity management techniques and develop an understanding of their condition.

At present no specific diagnostic test is available. 1,2,4-6 Diagnosis is made with reference to the symptoms and characteristics of prolonged fatigue, lethargy, weakness affecting daily life, muscle pain (myalgia), and altered thought processes, such as increased irritability and sensitivity to noise, distractibility, diminished concentration and decision making.2,5-7 The following case definition is generally used and accepted2:

... New onset of persistent or relapsing debilitating fatigue, ... severe enough to reduce or impair daily activity below 50% of the patient's premorbid activity level for a period of at least six months. All other clinical conditions that may produce similar symptoms excluded by thorough evaluation ... In addition, six or more of 11 identified

symptom criteria such as unexplained generalized weakness and muscle discomfort and two or more of three physical criteria must be fulfilled.

The theory and methods of cognitive behaviour therapy with chronic fatigue syndrome has been well documented.1,7,12,13 The patients current attitudes and beliefs are examinedl4 and the patient assisted to discover the most useful ways in managing and overcoming their illness, by identifying how the illness affects their thoughts, feelings and behaviours.13 The therapist and patient work together to plan strategies to deal with clearly identified problems with the emphasis placed on self-help.13,14

A gradual graded increase in activity has been suggested in the management of CFS7,9,15 to slowly re-establish sustained daily activity. A sudden return to activity following prolonged rest can produce an increase in the symptoms of fatigue and pain and then lead to an avoidance of exercise in an attempt to reduce the symptoms.1,13 In addition, individuals may have an exaggerated perception of their previous fitness and may overexert themselves in an effort to regain perceived previous fitness.16

Rest can be effective in reducing tiredness in the short term, however, in the long term it is less helpful as it reduces exercise tolerance and can produce increased weakness, muscle wasting, cardiac and respiratory difficulties and increased sensitivity to activity.7,9,17

The combined approach of cognitive behaviour therapy and graded activity considers both the psychological and physical factors associated with CFS13,18 and alternative therapies such as group therapy, exercise and relaxation used alone have been disappointing.19 The inpatient approach was adopted as previous attempts to treat patients in the outpatient department had been unsuccessful.

A maximum of four patients with CFS are admitted to the unit. All patients will have had substantially reduced functional ability for six months or longer and a history of febrile illness assumed viral in or around the onset of symptoms, fulfilling the criteria for CFS as described by Holmes et al.2

All patients are seen prior to admission in the neurological outpatient department at Oldchurch Hospital and Harold Wood Hospital (Havering Hospitals), Essex by the consultant neurologist (LJF).

On admission each patient has a full clinical examination, followed by haematological, biochemical and immunological screening, which includes haemoglobin full blood count, ESR, thyroid function, autoantibody screening, total and differential immunoglobulins, circulating immune complexes, coxsackie IgM and IgG antibody, VP1 antigen and glandular fever screen to identify possible causative agents and exclude any other cause for fatigue. Other tests are carried out according to clinical indications. In addition, all patients have auditory, visual and somatosensory evoked potentials, electroencephalography and CT brain scanning, and throughout their stay in hospital, the patients are under the direct care of the consultant neurologist (LJF).

All patients in the programme are offered a tricyclic antidepressant drug, in the form of trimipramine. There is some evidence to suggest that given as a single night dose (mean dose 50 mg, range 25-125 mg) the medication can improve symptoms such as myalgia and sleep disturbance, irrespective of depression.2,4,20,21

Each patient is assessed by an occupational therapist (OT), through observation and discussion, using a departmental functional checklist to establish the present level of daily functional ability. This information forms a baseline. With the OT the patient identifies their major difficulties and inhibiting problems, and the principles of the programme are introduced. Initial treatment goals are discussed and set by the patient and therapist. The goals are aimed at a realistic time scale and achievable level, and are upgraded when achieved and sustained, usually on a weekly basis.

Initially, introduction of activity may reproduce symptoms, therefore information and discussion on the possible effects of the treatment programme form the focus of the

initial treatment sessions. In order to sustain commitment the patients are encouraged to consider other reasons such as lack of fitness, for reduced ability.

Pacing of all activity is emphasized throughout the programme, to promote an understanding of the importance of the balance required between rest and effort. The aim, once this balance is established, is for activity to be carried out every day.1,13 Prior to admission patients often find themselves caught in a see-saw pattern of activity and rest, which is determined by the presence or absence of symptoms.1,9,13

Patients attend the OT department daily (Monday to Friday) to carry out selected functional, physical and/or cognitive tasks to slowly establish an improved activity level. A range of activities will be used, i.e. relaxation, remedial activities, cognitive games, printing, computer work and stool seating. The activities are up- or downgraded dependent upon the effect on the patient, the main gauge being a change in symptoms in the following 24-hour period.

Audit- method

A retrospective medical audit was carried out to indicate level of activity at six months following discharge from the inpatient programme described. A short checklist questionnaire was used to record personal details, level of ability and symptoms. Forty-four patients were seen over a two-year period between 1990 and 1992, and full information was available on 28 of these. The reasons that information was not available on the remaining 16 patients were: insufficient information recorded in medical records and nonresponse to a follow-up postal questionnaire (1), other diagnoses identified (3) and not having reached six months post discharge at the time of the audit (12).

Results

There were 21 females and seven males. The female mean age was 46 years with an age range of 24-78 years and male mean age was 34 years with an age range of 18-62 years. Table 1 indicates the distribution of age and gender.

Table 1 Gender and age range

	Age group in years			
	0-19	20-39	40-59	60+
Females n = 21	0	7	11	3
Males n = 7	1	4	1	1

The average length of stay in hospital was 34 days with a range of nine to 77 days and was not dependent upon age, gender or duration of symptoms.

The type of occupations are indicated in Table 2. Prior to admission 24 patients had changed their work pattern; 18 had time off work, two had changed to flexi-time, one had changed to part-time, one had reduced hours and two had reduced duties at work. Three patients (13%) had returned to work at time of the audit.

Table 2 Occupations

Occupations	Number of patients n = 28
Health, social care and teaching	7
Managerial/financial	5
Clerical	3
Skilled trade	4
Nonskilled worker	1
Housewife	3
Student	1
Retired (nonmedical)	3
Unemployed	1

The level of activity at six months following discharge is indicated in Table 3. Sixteen patients (57%) had an improved activity level at six months following discharge. The duration of symptoms compared with level of activity is shown in Table 4.

Table 3 Level of activity at six months following discharge

Level of activity	Number of patients n = 28
Symptoms worse/decrease in activity	2
Unchanged	10
Activity level 1 – symptoms reduced	4
Activity level 2 – increase in daily activities	9
Activity level 3 – return to work or school	3

Table 4 Duration of symptoms and level of activity

	Symptoms worse n = 2	Unchanged n = 10	Activity levels 1,2,3 n = 16
Average length of symptoms in years	5.5	6.4	4.4
Range in months	24-108	16-240	6-240

Discussion

The question, 'is CFS treatable in a NHS environment?' is largely unanswered, however we have tried to indicate an approach used in the treatment and management of patients with CFS. Few treatment approaches are available for CFS'1,13 that address the total disruption of daily life for these individuals and there is a lack of consensus of how CFS should be treated.1,7,13,15,23 The combination of graded activity and cognitive behaviour therapy discussed is one approach to treatment and management of CFS that could be beneficial.

A previous study22 has indicated that there is an increased prevalence of psychiatric disorder in patients with CFS, and that the psychological disturbance is likely to be a consequence rather than an antecedent risk factor to the syndrome. Both physical and psychological aspects of the syndrome, therefore, have to be addressed in treatment.

The audit showed that 57% of the patients had an improved activity level at six months following discharge, however due to the limitation of the audit, in particular the lack of controls, it is impossible to stipulate which factors influenced the patients. However, with no treatment, 72% of a study group had persistent fatigue and no functional improvement, after one year.23

Return to work can be difficult to achieve as employers often do not realize the length of time required prior to return to full time work.24 Seventy-five per cent of the patients studied who were in employment had stopped work prior to admission, at the time of the audit 13% had returned to work, indicating the possibility of return to previous levels of ability.

Research is required to consider the question of how duration of symptoms relates to outcome of treatment. Previously a duration of symptoms of longer than two years had a poor prognosis.25 The results of this audit and previous research2 has shown an improvement in daily activity for patients with a mean duration of symptoms of five years.

Conclusion

The audit had limitations as it was not a controlled study and the patient group was not studied during the treatment stage. However, with the limited resources of a single OT running the programme as part of a larger neurosciences caseload, we were able to show that 57% of patients indicated an improvement in level of ability at six months after discharge.

Further controlled study is proposed to examine the benefits and effect of the combined approach of graded activity and cognitive behaviour therapy on daily life for patients with CFS.

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