

ORIGINAL ARTICLE

Family cognitive behaviour therapy for chronic fatigue syndrome: an uncontrolled study

T Chalder, J Tong, V Deary

See end of article for authors' affiliations

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Correspondence to:
Dr T Chalder, Academic
Department of Psychological
Medicine, Guy's, King's and
St Thomas' School of
Medicine, 103 Denmark
Hill, London SE5 8AZ, UK;
t.chalder@iop.kcl.ac.uk

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Aim: To examine the efficacy of family focused cognitive behaviour therapy for 11-18 year olds with chronic fatigue syndrome.

Methods: Twenty three patients were offered family focused cognitive behaviour therapy. The main outcome was a fatigue score of less than 4 and attendance at school 75% of the time.

Results: Twenty patients completed treatment. Eighteen had completed all measures at six months follow up; 15 of these (83%) improved according to our predetermined criterion. Substantial improvements in social adjustment, depression, and fear were noted.

Conclusions: Family focused cognitive behaviour therapy was effective in improving functioning and reducing fatigue in 11-18 year olds. Gains were maintained at six months follow up.

Chronic fatigue syndrome (CFS), sometimes known as myalgic encephalomyelitis (ME), is a condition characterised by physical and mental fatigue which is made worse by exercise and is associated with profound disability.^{1,2} The consensus document issued by the three UK Royal Colleges considered that the diagnostic criteria developed for adults were equally applicable to children.³ Muscle pain, headache, sore throat, and increased somnolence are typical in children⁴⁻⁷ and disability can be profound. Children referred to specialist centres often have had long periods of time away from school, accompanied by impairment in social and leisure activities. Loss of peer relationships is frequent.⁵⁻⁷

There have been few studies on the natural history of CFS in children. Although a systematic review⁸ suggested that the prognosis is better in children than adults, with the majority making clinical improvements at two years, this is far from satisfactory given the impact on educational, physical, and social development. Left untreated, a substantial minority may develop long term psychological and physical disabilities.

The subjective, heterogeneous nature of CFS makes it likely that a complex interaction of physiological, cognitive, behavioural, affective, and social factors are responsible for both its development and maintenance. Research supporting this model is scarce. Two studies have noted a close connection between an exacerbation of symptoms and the start of a new term at school.^{9,10} However, clinical experience suggests that a number of events such as stress, overactivity, and a viral illness converge, resulting in the onset of severe fatigue. Subsequently, other influences, such as reducing activity caused by concern about making symptoms worse and inappropriate advice from health professionals, may inadvertently perpetuate the symptoms, leading to substantial disability. Cognitive behavioural treatment is derived from such an understanding of the condition. It involves enabling the patient to modify their cognitive and behavioural responses, such as fear and avoidance, which then alters their physiological response (fatigue).¹¹

A number of case studies and case reports have suggested that an effective approach involves a combination of behavioural interventions often linked with a family therapy approach.^{10,12-19} However, these studies have been limited by small numbers.

The aim of this study was to determine the effectiveness of family focused cognitive behaviour therapy in 11-18 year olds who fulfilled criteria for CFS. The hypothesis was that cognitive behaviour therapy would result in a return to school and reduction in fatigue.

METHODS

Participants

All patients (aged 11-18 years), recruited from consecutive referrals by general practitioners and consultant paediatricians, had been assessed by a paediatrician. Diagnosis of CFS was made according to the UK criteria,¹ but all participants met US consensus criteria as well.² Patients were excluded from the open trial, but not treatment, if they had life long problems of somatisation, severe depression with suicidal ideation, or self harming behaviour.

Outcomes

Outcome measures were assessed pre and post treatment and at six months follow up. The main outcome was attendance at school at least 75% of the time and a fatigue score of less than 4.²⁰ Subsidiary outcomes included the social adjustment questionnaire,²¹ the hospital anxiety and depression scale,²² the fear questionnaire,²³ and global self ratings of improvement and satisfaction with treatment.

The fatigue questionnaire is an 11 item scale which measures physical and mental fatigue. Each item is rated on a four option continuum from "less than usual" to "much more than usual". Scoring is bimodal, allowing a range of 0-11. A score of four or more indicates "caseness". The social adjustment scale measures the degree to which the fatigue impairs school, home, social, and private leisure activities. It is rated on a 0-8 scale; 8 represents severe impairment. The hospital anxiety and depression scale measures the two constructs and provides a score for each. The fear questionnaire provides a total fear score (range 0-120) with agoraphobia, social phobia, and blood and injury subscores (range 0-40). Global improvement was rated on a seven point scale from very much better to very much worse. Similarly satisfaction with treatment was rated on a seven point scale from very satisfied to very dissatisfied.

Intervention: a rehabilitation programme based on cognitive behaviour therapy

The main aim of treatment was to enable patients, with the help of their family, to carry out their own rehabilitation with some support and guidance from the therapist. Initially it involved the introduction of a consistent graded approach to

Abbreviations: CFS, chronic fatigue syndrome; ME, myalgic encephalitis

activity and establishing a sleep routine. Cognitive strategies were used when necessary. Parents were reassured about the safety of the approach and were given support in encouraging their child to engage in the rehabilitation process.¹¹

Throughout treatment the therapist focused on the end goal—a return to education full time. Temptations to explore other issues within the family (for example, difficulties within the parents' relationship) were resisted, unless it was clear that progress would have been facilitated by such a diversion.

Structure

Families were seen fortnightly for up to 15 hourly sessions of face to face treatment. Follow ups were carried out at three and six months and then one year to monitor progress and tackle any residual problems. At every session short term goals were agreed on. Problems were anticipated and problem solving strategies used to elicit effective coping.

Activity scheduling

Goals usually included a mixture of social, school, and leisure related activities. Short walks or tasks carried out in even chunks throughout the day were interspersed with rests. The emphasis was on consistency and breaking the association between experiencing symptoms and stopping activity. The goals (for example, walking for 10 minutes three times daily) were gradually built up as tolerance to symptoms increased, until the longer term targets were reached. Tasks such as reading or school work, which require concentration, were included in the programme.

Establishing a sleep routine

Early on in treatment patients were asked to keep a diary of bedtime, sleep time, wake up time, and get up time. The total number of hours spent asleep was calculated and a variety of strategies were then used to improve quality and quantity of sleep. A routine of going to bed and getting up at a preplanned time, while simultaneously cutting out daytime catnaps, helped to improve both hypersomnia and insomnia.

Modifying negative and unhelpful thinking

The main aim of this component was to prevent unhelpful thoughts from blocking progressive increases in activity. Explanations regarding the physiological effects of inactivity helped families to understand the rationale for activity scheduling. Negative aspects of perfectionism and cognitive errors such as all or nothing thinking were addressed.

Relapse prevention

During the last few sessions strategies for dealing with setbacks—that is, an exacerbation of symptoms, were discussed. Typically, during treatment, patients experienced a worsening of symptoms during a viral infection or a stressful event such as an examination at school. They were encouraged to continue with

activities, but not exercise, when they had a virus and were given written information about how to aid study.

Statistical analysis

Medians and interquartile ranges were calculated for all continuous outcomes. Pretreatment and six month follow up scores were compared using the Wilcoxon signed rank test. Proportions were calculated for the main outcome and global ratings.

RESULTS

Patient characteristics

Forty patients were referred to the CFS research and treatment unit at King's College Hospital. Seven did not attend or cancelled the assessment. Thirty three consecutive 11–18 year olds were assessed. Of these, three reported symptoms for most of their life and two had persistent behavioural problems such as deliberate self harm. Three had too far to travel regularly for treatment. Two were given advice because they had less severe problems. These were excluded from the pilot study. Twenty three patients were offered family focused cognitive behaviour therapy (graded activity, establishing a sleep routine, and cognitive restructuring). Three dropped out of treatment after a few sessions. Twenty completed treatment. Eighteen completed measures pre and post treatment and at six months follow up. The two others who completed treatment were contacted at home by telephone. They informed us that they were back at school full time.

The median age of the 23 youngsters at assessment was 15 years (interquartile range 14–17). Twenty were girls and three were boys. Four were depressed and two had an anxiety disorder on clinical assessment. Five were prescribed antidepressants during therapy. Sixteen of the 18 who completed measures (89%) attributed the onset of their fatigue to a viral infection. Median length of illness was two years (range 0.5–5).

Proportion of patients improved

At six months follow up, 83% of patients (15/18), for whom we had measures of school attendance and fatigue scores, improved according to our criterion for improvement (fatigue <4 and going to school 75% of the time). All 20 who completed treatment had returned to school at six months follow up; 95% were at school full time.

Pattern of change

Table 1 shows the median scores on all outcome variables at pre and post treatment, and follow up. Most patients reported changes in fatigue, social adjustment, fear, and depression.

Self rated global improvement at final follow up (table 2) was consistent with outcome on the other measures of fatigue, social adjustment scale, mood, and fear. Attributions did not alter as a result of treatment. All 16 who made a viral attribution at baseline continued to hold the same belief at discharge and follow up.

Table 1 Median (interquartile range) scores for fatigue, social adjustment, anxiety, and depression

	Pretreatment (n=18)	Post treatment (n=15)	6 month follow up (n=18)	Wilcoxon signed ranks test (z score)	Significance (2-tailed)
SA—total (4)	20.5 (12.7, 26.5)	6 (3, 8)	3 (0, 7.5)	-3.51	0.00
Fatigue Q (11 items) (0,0,1,1)	9.5 (6.2, 11)	2 (0, 6)	0.5 (0, 3)	-3.51	0.00
Anxiety (HAD)	7 (6.7, 9.7)	4.9 (4.22, 5.49)	0.5 (0.5, 9)	-2.02	0.04
Depression (HAD)	8.3 (5.7, 11)	5.1 (3.0, 7.2)	3 (3, 5)	-3.33	0.00
Fear—agoraphobia	12.9 (8, 17.8)	6.4 (3.2, 9.5)	4.8 (2.2, 7.4)	-2.85	0.00
Fear—blood/injury	9.9 (5.7, 14.2)	5.7 (2.7, 8.7)	6.9 (2.9, 10.8)	-1.57	0.12
Fear—social	12.2 (8.8, 15.6)	7.4 (4.4, 10.5)	8.5 (4.7, 12.2)	-1.42	0.16
Fear—total	35.1 (26.2, 43.9)	19.5 (12.4, 26.6)	20.2 (11.5, 28.9)	-2.15	0.03
Fear—dysphoria	11.7 (7.0, 16.4)	6.9 (3.0, 10.7)	6.3 (2.9, 9.8)	-1.58	0.11
Number of days at school or work	0.5 (0.0, 3.5)		5.0 (5.0, 5.0)	-3.57	0.00

SA, social adjustment; HAD, Hospital Anxiety and Depression Scale.

Table 2 Self rated global improvement

Global rating	Description	Post treatment (n=15)	6 month follow up (n=18)
Global improvement	Very much and much better	92.3%	100%
	A little better	7.7%	0%
Global satisfaction with treatment	Very, moderately	100%	100%

DISCUSSION

The aim of this study was to report the results of an open trial of family focused cognitive behaviour therapy for 11–18 year olds with CFS. The study was thus subjected to all the deficiencies of a non-blind, non-randomised study. Of the 40 who were initially referred a substantial number failed to attend the initial assessment. A further 10 were not suitable for the trial because of distance to travel to the hospital, behavioural problems, or chronic somatic complaints. This resulted in 25 eligible patients. Data were not available for those who received advice or those who dropped out of treatment. For these reasons the results must be interpreted cautiously. However, substantial improvement in school attendance, fatigue, social adjustment, depression, and fear occurred in the majority who completed treatment. The improvements occurred by discharge and were maintained to six months follow up.

Although the prognosis of CFS in children is good in a paediatric setting,⁶ most follow up studies have been conducted on youngsters whose fatigue is of short duration and a substantial minority still require additional treatment. Given that the 11–18 year olds in this study had been ill for a mean of 2.4 years, the observed improvements were unlikely to have been caused by chance alone. It is impossible to deduce the precise mechanism of change. It is possible that non-specific factors such as therapist time and attention were responsible for the improvements seen. However, results of randomised controlled trials in adults do not support this hypothesis.^{24–27}

A prospective study of CFS in adolescents found significantly more anxiety disorders in recovered patients.²⁸ In this study changes in fatigue and social adjustment were synchronous with changes in fear as measured by the fear questionnaire. We directly address fearful cognitions about the meaning of symptoms, but where patients are reluctant to acknowledge the role of anxiety or depression we avoid labelling the symptoms as anxiety. Rather, we attempt to normalise the experience of somatic symptoms and encourage children and their families not to catastrophise in response to them.

Contrary to popular belief it is not necessary to directly challenge individuals' or families' beliefs about the aetiology of the illness.²⁹ Specific cognitions about the danger of activity and exercise can be examined and if appropriate addressed. Joining and accommodating to the family's beliefs is far more advantageous to the process of change. The therapist models positive reinforcement, patient persistence, and optimism. Although the approach is largely child focused, all family members need to be supported throughout treatment.

To our knowledge, the current study is the first of this size to evaluate the effectiveness of cognitive behaviour therapy for adolescents with CFS, delivered within the context of the family. The approach is now being evaluated in a randomised controlled trial.

Authors' affiliations

T Chalder, Academic Department of Psychological Medicine, Guy's, King's and St Thomas' School of Medicine, 103 Denmark Hill, London SE5 8AZ, UK

J Tong, V Deary, The Chronic Fatigue Syndrome Research and Treatment Unit, South London and Maudsley NHS Trust, UK

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