



# Family-focused cognitive behaviour therapy versus psycho-education for adolescents with chronic fatigue syndrome: Long-term follow-up of an RCT

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## ABSTRACT

The aim of this study was to investigate the long term efficacy of family-focused cognitive behaviour therapy (CBT) compared with psycho-education in improving school attendance and other secondary outcomes in adolescents with chronic fatigue syndrome (CFS). A 24 month follow-up of a randomised controlled trial was carried out. Participants received either 13 one-hour sessions of family-focused CBT or four one-hour sessions of psycho-education. Forty-four participants took part in the follow-up study. The proportion of participants reporting at least 70% school attendance (the primary outcome) at 24 months was 90% in CBT group and 84% in psycho-education group; the difference between the groups was not statistically significant ( $OR = 1.29, p = 0.80$ ). The proportion of adolescents who had recovered in the family-focused CBT group was 79% compared with 64% in the psycho-education, according to a definition including fatigue and school attendance. This difference was not statistically significant (Fisher's exact test,  $p = 0.34$ ). Family-focused CBT was associated with significantly better emotional and behavioural adjustment at 24 month follow-up compared to psycho-education, as reported by both adolescents ( $F = 6.49, p = 0.02$ ) and parents ( $F = 4.52, P = 0.04$ ). Impairment significantly decreased in both groups between six and 24 month follow-ups, with no significant group difference in improvement over this period. Gains previously observed for other secondary outcomes at six month follow-up were maintained at 24 month follow-up with no further significant improvement or group differences in improvement. In conclusion, gains achieved by adolescents with CFS who had undertaken family-focused CBT and psycho-education generally continued or were maintained at two-year follow-up. The exception was that family-focused CBT was associated with maintained improvements in emotional and behavioural difficulties whereas psycho-education was associated with deterioration in these outcomes between six and 24-month follow-up.

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## Introduction

Chronic fatigue syndrome (CFS) is characterised by severe disabling fatigue, present for more than 50% of the time and affecting both physical and mental functioning, which is not accounted for by organic illness. It is typically accompanied by other symptoms such as headaches, sleep problems, difficulties with concentration and musculoskeletal pain and must be present for at least six months for a diagnosis to be made (Fukuda et al., 1994). In children and adolescents the condition presents in the

same way but need only be present for a minimum of three months to be diagnosed (Royal College of Physicians, 1996).

Prognosis in young people has been found to be relatively good and favourable in comparison to that in adults (e.g. Joyce, Hotopf, & Wessely, 1997; Rimes et al., 2007). However CFS in children and adolescents is associated with serious impairment (Garraalda & Rangel, 2004) with effects on physical, emotional and intellectual development (Royal College of Physicians, 1996). It is associated with significant absenteeism from school (Patel, Smith, Chalder, & Wessely, 2003; Wright & Cottrell, 1997) as well as withdrawal and isolation (Carter, Edwards, Kronenberger, Michalczyk, & Marshall, 1995).

Cognitive behavioural models of CFS in adolescents (e.g. Chalder, Tong, & Deary, 2002) suggest that the onset of the condition is often associated with psychosocial stress along with an acute illness. Cognitive, behavioural, physiological, emotional and social factors are then seen as interacting to perpetuate symptoms and prevent recovery. Cognitive behaviour therapy (CBT) for chronic fatigue

Abbreviations: CFS, chronic fatigue syndrome; CBT, cognitive behaviour therapy.

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syndrome is aimed at addressing these contributory factors and typically involves planned activity and rest, a graded increase in activity, establishing a sleep routine and addressing any unhelpful beliefs (Chalder et al., 2002; Rimes & Chalder, 2005).

The results of a randomised controlled trial comparing family-focused CBT with psycho-education were previously reported (Chalder, Deary, Husain, & Walwyn, 2010). This was one of only three RCTs (Chalder et al., 2010; Nijhof, Bleijenberg, Ulterwaal, Kimpfen, & van de Putte, 2012; Stulemeijer, de Jong, Fiselier & Bleijenberg, 2005) investigating the effectiveness of CBT in adolescents, but the only one to compare CBT with another active treatment. Whilst adolescents receiving family-focused CBT were found to have greater improvement in school attendance at end of treatment than those receiving psycho-education, at six month follow-up both groups had improved to the same extent.

There is to date only one other study investigating the long-term effectiveness of CBT for adolescents with CFS. Knoop, Stulemeijer, de Jong, Fiselier, and Bleijenberg (2008) found benefits associated with CBT in terms of fatigue, physical functioning and school attendance at two year follow-up in comparison to a group who declined CBT after a waiting list period. The present study extends previous research in including an active control intervention.

## Methods

### Participants

63 11 to 18-year olds referred to King's College Hospital London and fulfilling either the Oxford or CDC criteria for CFS (Fukuda et al., 1994; Sharpe et al., 1991) took part in the original trial and were randomly assigned to family-focused CBT ( $n = 32$ ) or psycho-education ( $n = 31$ ). 44 of the participants from the original study (24 in the CBT group and 20 in the psycho-education group) agreed to take part in the two year follow-up. Of the remaining participants who took part in the original trial, 14 declined to take part, whilst five were not contactable. The follow-up rate at 24 month follow-up was 70% of those participating in the original trial. Table 1 shows baseline demographics for those participating in the follow-up study.

### Ethical approval

Ethical approval was given by the Joint South London and Maudsley and Institute of Psychiatry Research Ethics Committee (reference 003/03).

### Setting

Participants were recruited from a specialist chronic fatigue syndrome service.

### Procedure

Participants taking part in the original study were contacted by post and invited to take part in the follow-up study. Outcomes were assessed using questionnaire booklets containing self-report measures which were sent out by and returned to a research

assistant in order to reduce information bias. Further details regarding the original trial, including the randomisation process, are described in Chalder et al. (2010).

### Interventions

#### Family-focused CBT

A family-focused approach to treating CFS in adolescents was developed (Chalder, 1999; Chalder et al., 2002). The intervention involved 13 one-hour sessions which were delivered every fortnight and typically involved a) encouraging a balance between activity and rest, b) gradually increasing activities – including school, home and social life, c) establishing a sleep routine, d) addressing unhelpful beliefs, e) encouraging family members to express their own views about the illness and agreeing a way forward, and f) paying attention to relapse prevention. Families were given a treatment manual and homework assignments were discussed with adolescents at each session.

#### Psycho-education

Psycho-education involved four one-hour sessions over a period of six months. Whilst the content of the psycho-education intervention was similar to that of the CBT group, the mode of delivery was didactic. Discussion, information giving and problem solving were included but homework assignments and cognitive restructuring did not feature and families were not given a manual.

A checklist was used which ensured that therapists delivered the following: a) gave the message that untreated CFS in adolescents has a good prognosis, b) presented a model of CFS that distinguished predisposing, precipitating and maintaining factors, c) introduced the concept of symptom management, i.e. that the way that physical symptoms are managed makes a difference to outcome, d) physical illness analogies such as heart disease were used to increase likelihood of engagement, e) advice on pacing and consistency of activity and rest, f) advice on sleep management, g) conveying the message that increased symptoms do not mean more pathology, h) advice on gradually building up activity over a period of months.

Both interventions were delivered by two trained cognitive behaviour psychotherapists.

### Aims and hypotheses

The primary aim of the study was to compare the long-term (24 month follow-up) efficacy of family-focused CBT with that of psycho-education in improving school attendance and other secondary outcomes. It was hypothesised that family-focused CBT would be more efficacious at long term follow-up compared with psycho-education in terms of school attendance and secondary outcomes. Although in the original trial no difference was found between the two interventions at six month follow-up, this prediction was based on the nature of family-focused CBT as a more intensive intervention. It was also predicted that a greater proportion of participants in the CBT group would be classed as 'recovered' at 24 month follow-up compared to the psycho-education group.

**Table 1**  
Baseline demographics.

	Family-focused CBT ( $n = 24$ )	Psycho-education ( $n = 20$ )	Total
Gender – female (%)	$n = 18$ (69%)	$n = 14$ (67%)	$n = 32$ (68%)
Age (years)	Mean (SD) 15.00 (1.47)	15.00 (2.00)	15.00 (1.71)
Illness duration (months)	Median (IQR) 24.00 (14.00–36.00)	19.00 (12.00–36.00)	24.00 (12.00–36.00)

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