



Telephone-based guided self-help for adolescents with chronic fatigue syndrome: A non-randomised cohort study

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ABSTRACT

The aim of this study was to gain preliminary evidence about the efficacy of a new telephone-based guided self-help intervention, based on cognitive-behavioural principles, which aimed to reduce fatigue and improve school attendance in adolescents with chronic fatigue syndrome (CFS). A non-randomised cohort design was used, with a two-month baseline period. Sixty-three 11–18 year-old participants recruited from a specialist CFS unit received the intervention. Participants received six half-hour fortnightly telephone sessions and two follow-up sessions. Fatigue and school attendance were the main outcomes and the main time point for assessing outcome was 6 months post-treatment. Using multi-level modelling, a significant decrease in fatigue was found between pre-treatment and 6 month follow-up, treatment effect estimate = -5.68 ($-7.63, -3.72$), a large effect size (Cohen's $d = 0.79$). The decrease in fatigue between pre and post-treatment was significantly larger than between baseline and pre-treatment. A significant increase in school attendance was found between pre-treatment and 6 month follow-up, effect estimate = 1.38 ($0.76, 2.00$), a medium effect size ($d = -0.48$). Univariate logistic regression found baseline perfectionism to be associated with poorer school attendance at six-month follow-up. In conclusion, telephone-based guided self-help is an acceptable minimal intervention which is efficacious in reducing fatigue in adolescents with CFS.

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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 for a diagnosis to be made (Royal College of Physicians, 1996).

CFS in children and adolescents is associated with serious impairment, (Garralda & Rangel, 2004) with potential adverse 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).

Despite considerable research, the aetiology of CFS remains uncertain and controversial, (Browne & Chalder, 2006) although it is likely that both the development and perpetuation of the disorder are due to an interaction of cognitive, behavioural, physiological, affective and social factors (Chalder, Tong, & Deary, 2002a). Cognitive behavioural models of CFS (e.g. Surawy, Hackman, Hawton, & Sharpe, 1995; Wessely, Butler, Chalder, & David, 1991) provide a multifactorial explanation of the condition and make a distinction between factors which predispose and those which perpetuate the condition. It is suggested that the onset of the condition is often associated with psychosocial stress along with an acute illness, with a combination of cognitive, behavioural, physiological, emotional and social factors interacting to perpetuate symptoms and impede recovery (Surawy et al., 1995). In terms of predisposing factors, it is suggested that individuals who tend to believe that their worth and acceptance by others is contingent on maintaining very high standards of performance and behaviour (sometimes called 'negative perfectionism'), may be more

Abbreviations: CFS, Chronic Fatigue Syndrome; CBT, Cognitive Behaviour Therapy.

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vulnerable to developing CFS in the context of acute illness or stress. Consistent with this suggestion, a recent prospective study found that higher levels of negative perfectionism at the time of a glandular fever infection were associated with increased risk of developing CFS six months later (Moss-Morris, Spence, & Hou, 2011). It is suggested that such individuals are more likely to experience distress, with accompanying physical symptoms, if their goals are blocked and may tend to keep pressing on with their striving despite increasing fatigue (Surawy et al., 1995). The prospective study also found that levels of depression, anxiety and somatisation at the time of a glandular fever infection predicted new onset CFS six months later (Moss-Morris et al., 2011).

Cognitive behavioural approaches also suggest that unhelpful beliefs about symptoms can lead to coping behaviours which can inadvertently maintain the fatigue (Butler, Chalder, Ron, & Wessely, 1991; Clements, Sharpe, Simkin, Borrill, & Hawton, 1997; Surawy et al., 1995). For example, if an individual fears that undertaking exercise or stressful activities will worsen their fatigue then avoiding such activities is understandable and may help to avoid increases in fatigue in the short-term. However in the long-term, excessive resting or avoiding activities can perpetuate symptoms and increases the risk of chronic fatigue syndrome (e.g. Candy et al., 2002). Strenuous attempts to meet previous levels of performance, leading to increased exhaustion and the necessity to rest, followed by further attempts to undertake high levels of activity (sometimes called 'boom or bust' behaviour) are also common in CFS. There is evidence that this behavioural pattern at the time of an acute glandular fever infection is associated with increased risk of developing CFS (Moss-Morris et al., 2011).

Cognitive behaviour therapy (CBT) for chronic fatigue syndrome is aimed at addressing such contributory factors and typically involves planned activity and rest, a graded increase in activity, establishing a sleep routine and addressing any unhelpful beliefs (Rimes & Chalder, 2005). For example, as activity is slowly increased beliefs concerning the link between increased activity and worse physical symptoms can be tested.

Two randomised controlled trials have found CBT to be effective in reducing fatigue and improving school attendance in young people with CFS (Chalder, Deary, Husain, & Walwyn, 2010; Stulemeijer, de Jong, Fiselier, Hoogveld, & Bleijenberg, 2005). Improvements in other domains such as depression, anxiety and adjustment were also reported (Chalder et al., 2010). Whilst these findings are promising, attendance at regular face-to-face appointments is not always possible. Many young people with CFS report difficulty accessing specialist units because they do not feel well enough to travel to the unit or find that the travelling exacerbates their symptoms. Therefore there is a need to develop evidence-based interventions which provide an alternative for adolescents for whom traditional clinic-based sessions are unsuitable. One option may be guided self-help over the telephone, the subject of this current evaluation.

There is increasing evidence for the effectiveness of "low-intensity" CBT interventions as a first step or a more accessible alternative in the treatment of a range of problems. CBT-based guided self-help has been shown to be effective in treating both anxiety and depression. A systematic review of guided self-help for adults with anxiety and/or depression found this type of intervention to have comparable effects to face-to-face psychotherapy, including face-to-face CBT (Cuijpers, Donker, van Straten, Li, & Andersson, 2010).

Preliminary studies have shown guided self-help delivered via the telephone to have promising results in anxiety disorders (Creswell et al., 2010; Lyneham & Rapee, 2006) and OCD (Turner, Heyman, Furth et al., 2009) in adolescents. After an initial pilot study (Burgess & Chalder, 2001) a randomised controlled trial of telephone treatment versus face-to-face treatment for adults with

CFS (Burgess, Andiappan, & Chalder, 2011; Burgess & Chalder, 2001) resulted in decreased fatigue, anxiety and depression and improvements in work and social functioning in those who had telephone treatment as well as those who had face-to-face.

To our knowledge, no predictors of treatment outcome have been identified for adolescents with CFS. In adults, there is inconsistent evidence regarding the role of psychological problems in predicting outcome; for example Butler et al. (1991) and Kempke et al. (2010) found that pre-treatment depression predicted poor outcome for fatigue following treatment, whereas other studies (e.g. Deale, Chalder, Marks, & Wessely, 1997) found that psychiatric conditions at baseline did not predict outcome. In studies of other problems it has been found that perfectionism is a significant predictor of treatment outcomes. For example, in adults, higher levels of perfectionism have been found to be associated with poorer prognosis five to ten years after inpatient treatment for eating disorders (Bizeul, Sadowsky, & Rigaud, 2001). In a study of adolescents with depression, Jacobs et al., 2009 found that adolescents with higher levels of perfectionism at baseline experienced less improvement in terms of depression and suicidality in response to treatment.

No previous studies have examined perfectionism as a predictor of outcome in adolescents with CFS. Maternal mental distress has previously been found to be associated with higher risk of developing chronic fatigue in a community study (Rimes et al., 2007) but to our knowledge there is no existing research which has examined maternal mental wellbeing as a predictor for treatment outcome. Studies outside of treatment settings with adults have found mixed results for factors such as illness severity and age as predictors of recovery from fatigue (Cairns & Hotopf, 2005).

Aims and hypotheses

The primary aim of the present study was to investigate the efficacy of a new telephone-based guided self-help intervention in reducing fatigue and increasing school attendance in 11- to 18-year-olds meeting the Oxford criteria for CFS (Sharpe et al., 1991). It was predicted that there would be significantly greater decreases in fatigue and increases in school attendance between pre-treatment and post-treatment than between baseline and pre-treatment, which would give preliminary indication of the efficacy of the intervention. The primary outcome time point was 6 months post-treatment, with end of treatment and 3 month follow-up also investigated. Secondary outcomes were impairment, depression, anxiety and adjustment.

A further aim was to investigate whether baseline perfectionism and maternal distress were associated with poorer fatigue and school attendance outcomes. Baseline depression, anxiety, length of illness, impairment, adjustment, age and gender were also investigated as potential predictors of outcome but predictions were not made as previous research has found inconsistent relationships between such factors and recovery. The amount of the handbook that participants reported reading was also investigated as a potential predictor of outcome. A further study aim was to investigate adolescents' and parents' perceptions of overall improvement as a result of the intervention, overall satisfaction with the treatment they had received and the feasibility of a telephone intervention in terms of patient availability for telephone sessions and completion of the course of treatment.

Methods

Participants

Consecutive patients aged 11- to 18 years of age, referred to the King's College Chronic Fatigue Unit in London, who fulfilled criteria

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