



Prevalence and predictors of recovery from chronic fatigue syndrome in a routine clinical practice



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ABSTRACT

Cognitive behavioural therapy (CBT) is one of the treatments of choice for patients with chronic fatigue syndrome (CFS). However, the factors that predict recovery are unknown.

The objective of this study was to ascertain the recovery rate among CFS patients receiving CBT in routine practice and to explore possible predictors of recovery.

Recovery was defined as no longer meeting Oxford or CDC criteria for CFS measured at 6 months follow-up. A composite score representing full recovery additionally included the perception of improvement, and normal population levels of fatigue and of physical functioning. Logistic regression was used to examine predictors of recovery. Predictors included age, gender, cognitive and behavioural responses to symptoms, work and social adjustment, beliefs about emotions, perfectionism, anxiety and depression at baseline.

At 6 months follow-up 37.5% of the patients no longer met either the Oxford or the CDC criteria for CFS while 18.3% were fully recovered. Multivariate analyses showed that worse scores on the work and social adjustment scale, unhelpful beliefs about emotions, high levels of depression and older age were associated with *reduced* odds for recovery.

Recovery rates in this routine practice were comparable to previous RCTs. There was a wide spectrum of significant predictors for recovery.

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Chronic fatigue syndrome (CFS) is a heterogeneous and multi-factorial condition, characterised by fatigue and disability. Two commonly used criteria are; the Oxford criteria (Sharpe et al., 1991), and the US Center for Disease Control (CDC) criteria (Fukuda et al., 1994). While these two criteria are similar, there is not a complete overlap in terms of included symptoms. The CDC criteria necessitate the presence of several discrete symptoms. The Oxford criteria are less “detailed” in this respect but require the presence of both physical and mental fatigue for 6 months or more.

The aetiology is still much debated with some focused on finding a specific cause (Cairns & Hotopf, 2005). Since CFS does not have pathognomonic manifestations, the diagnostics of CFS remains a clinical endeavour, and suggests that the condition may be multi-factorial. Our original cognitive behavioural model of CFS

suggested that an initial trigger such as a virus may contribute to a vicious cycle in which the individual avoids activity for fear of making symptoms worse (Butler, Chalder, Ron, & Wessely, 1991). In an effort to manage symptoms people become hypervigilant and this so called symptom focussing can exacerbate symptoms (Chalder, Butler, & Wessely, 1996). Surawy and colleagues subsequently added to the model by suggesting that pre-morbid characteristics such as conscientiousness and perfectionism contributed to individuals becoming vulnerable. In addition, patients with CFS were more likely to hold the belief that showing emotions was unacceptable (Surawy, Hackmann, Hawton, & Sharpe, 1995). Cognitive behavioural therapy (CBT) addresses these factors but in particular focuses on encouraging patients to become more consistent in engaging in activity before increasing activity thereby challenging fearful cognitions such as fear avoidance beliefs and catastrophising whilst simultaneously addressing symptom focussing. CBT and graded exercise therapy (GET) have proven to be the most effective treatments for CFS with significant improvements in fatigue and disability (Chambers, Bagnall, Hempel, & Forbes, 2006; White et al., 2011). However, reduction

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in symptoms and improvement from disability does not necessarily entail recovery.

Recovery as an outcome has rarely been investigated in CFS patients. Recovery involves several conditions such as perception of improvement, perception of symptom reduction and perception of improvement of fatigue impact. More objectively, recovery entails no longer meeting the Oxford and the CDC CFS criteria. To recover may represent a return to pre-morbid levels of health and wellbeing. When previously defining recovery from CFS, studies have used the normal population statistics as a guide. However, for some CFS patients recovery as defined by the population mean may entail a level of good health they did not have before their CFS started. Likewise, “healthy” individuals could regard themselves as fully functional and still be under the population mean on health questionnaires. Some studies have thus set the cut-off for recovery at 1 standard deviation (SD) from the population mean (Deale, Husain, Chalder, & Wessely, 2001; Knoop, Bleijenberg, Gielissen, van der Meer, & White, 2007).

Early studies found that up to a quarter of people with CFS who receive CBT in the context of a randomized controlled trial (RCT) make a full recovery (Deale et al., 2001; Knoop, Bleijenberg, et al., 2007). Although Deale and colleagues found that patients recovered there was a slight downward trajectory from the 1 to 5 year follow-up (Deale et al., 2001). More recently a large multi-centred four-arm RCT found that 22% of patients in secondary care recovered after CBT, 22% after GET, 8% after adaptive pacing therapy (APT) and 7% after specialist medical care (White, Goldsmith, Johnson, Chalder, & Sharpe, 2013). The odds for recovery after CBT or GET were 3.36 and 3.38 respectively when compared to APT. This study confirmed that recovery from CFS was possible.

Outside the confines of an RCT clinical follow-ups have found that between 0% and 31% of the CFS patients show full recovery depending on the setting (Cairns & Hotopf, 2005). In Cairns and Hotopf (2005) systematic review covering various clinical follow-ups, they found a median of 5% showing full recovery and 39.5% showing improvement (Cairns & Hotopf, 2005). However, the studies used different inclusion criteria. Some were conducted in primary care whereas others were secondary care studies. Some of the highest recovery rates were found in primary care settings, possibly involving lower levels of severity or chronicity than those treated in secondary care. In addition, the studies involved different types of treatment many of which were not recorded systematically.

The variation in recovery rates in different studies is likely to be affected by the inclusion criteria used. Furthermore, the recovery rate will be influenced by the operationalization of “full recovery” and the timing of follow-ups in the different studies.

Predictors of outcome after CBT

Several studies have examined predictors of outcomes after CBT. A recent study examined heterogeneity in terms of symptom clusters and their association with fatigue outcome. This study indicated that characteristics in CFS patients may affect responsiveness to CBT (Cella, Chalder, & White, 2011). They found that a higher frequency of weight fluctuation, physical shaking, pain and anxiety together with higher levels of symptom focussing were predictive of a negative outcome. Similarly, symptom focussing and a passive activity pattern had previously been found to predict less improvement in a randomised controlled trial of CBT (Prins et al., 2001).

Psychiatric disorders like depression and anxiety represent the most common co-morbid disorders among CFS patients, and have been linked to outcome after CBT (Kempke et al., 2010; Prins, Bleijenberg, & Rouweler, 2005; Sharpe, Hawton, Seagroatt, & Pasvol, 1992). An association between maltreatment and CFS

(Nater et al., 2009) has been found and this may explain some of the co-morbid anxiety and depression seen in CFS. Interestingly though, only those people with CFS and childhood trauma had low cortisol (Nater et al., 2009). Although low cortisol showed a poor response to CBT in one study (Roberts et al., 2010) reassuringly the presence of maltreatment did not affect the outcome of CBT for people with CFS in another (Heins, Knoop, Lobbetael, & Bleijenberg, 2011).

A number of other factors have been associated with outcome after CBT. Patients who believe that their illness is primarily physical are more likely to have a poorer outcome after CBT (Butler et al., 1991). Older age has been associated with a poorer outcome (Quarby, Rimes, Deale, Wessely, & Chalder, 2007) as has being in receipt of disablement insurance benefit (Bentall, Powell, Nye, & Edwards, 2002) or being involved in a legal procedure related to financial benefits (Prins, Bazelmans, Van der Werf, Van de Meer, & Bleijenberg, 2001). Focussing specifically on recovery, data from two randomized controlled trials were used to examine the association between pain and outcome from CBT. Recovered adult patients had fewer pain locations following treatment but higher pain severity at baseline was associated with a negative treatment outcome (Knoop, Stulemeijer, Prins, van der Meer, & Bleijenberg, 2007).

In the present study we aimed to investigate recovery rates in patients who received CBT at a secondary care CFS treatment unit in routine clinical practice. We looked at differences in recovery rates at the 6 month follow-up according to different indicators of recovery: i) the CDC and the oxford criteria, ii) levels of fatigue, iii) physical disability and iv) subjective experience of improvement. We furthermore aimed to investigate the association between the different indicators of recovery and the following predictors: age, gender, duration of CFS, anxiety, depression, perfectionism, symptom/illness acceptance, beliefs about emotions, work and social adjustment and cognitive and behavioural responses to symptoms. These variables were chosen as they represented aspects of the cognitive behavioural model of CFS and also took account of the previous research findings. Univariate associations were initially explored. However, subsequently variables included in the multi-variable analysis were those that were significant at 0.1. We predicted that the presence of distress in the form of anxiety or depression, symptom focussing, more avoidance behaviour and unhelpful perfectionism would be associated with not recovering.

Method

Participants

The participants in this study were CFS patients who were treated with CBT at the Chronic Fatigue Syndrome Unit at South London and Maudsley, NHS Trust. Outcomes after CBT are measured routinely and audit approval was given by the Psychological Medicine Clinical Academic Group (CAG) at the South London and Maudsley Hospital to examine predictors of outcome.

All of the participants were diagnosed with CFS in accordance with the NICE guidelines (Turnbull et al., 2007) and assigned to CBT based on a clinical assessment. At pre-treatment assessment, all participants fulfilled the NICE guidelines for the CFS criteria (having fatigue for the last 4 months), 72.7% met the Oxford criteria and 52.6% of the participants met the CDC criteria. This non-randomized cohort included 200 CFS patients whose treatment was initiated before August of 2010.

In this study CBT was based on the illness model of fear avoidance, as described in the PACE protocol (White, Sharpe, Chalder, DeCesare, & Walwyn, 2007). The model involved these fundamental elements: (i) reviewing beliefs about the illness and coping strategies, (ii) re-establishing a stable baseline of general activities

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