



## The process of cognitive behaviour therapy for chronic fatigue syndrome: Which changes in perpetuating cognitions and behaviour are related to a reduction in fatigue?

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### ABSTRACT

**Objective:** Cognitive behaviour therapy (CBT) can significantly reduce fatigue in chronic fatigue syndrome (CFS), but little is known about the process of change taking place during CBT. Based on a recent treatment model (Wiborg et al. J Psych Res 2012), we examined how (changes in) cognitions and behaviour are related to the decrease in fatigue.

**Methods:** We included 183 patients meeting the US Centers for Disease Control criteria for CFS, aged 18 to 65 years, starting CBT. We measured fatigue and possible process variables before treatment; after 6, 12 and 18 weeks; and after treatment. Possible process variables were sense of control over fatigue, focusing on symptoms, self-reported physical functioning, perceived physical activity and objective (actigraphic) physical activity. We built multiple regression models, explaining levels of fatigue during therapy by (changes in) proposed process variables.

**Results:** We observed large individual variation in the patterns of change in fatigue and process variables during CBT for CFS. Increases in the sense of control over fatigue, perceived activity and self-reported physical functioning, and decreases in focusing on symptoms explained 20 to 46% of the variance in fatigue. An increase in objective activity was not a process variable.

**Conclusion:** A change in cognitive factors seems to be related to the decrease in fatigue during CBT for CFS. The pattern of change varies considerably between patients, but changes in process variables and fatigue occur mostly in the same period.

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### Introduction

Chronic fatigue syndrome (CFS) is diagnosed when someone experiences medically unexplained, severe fatigue that has been present for at least six months and results in severe impairment in daily functioning. The fatigue is accompanied by at least four out of eight of the following symptoms: post-exertion malaise, unrefreshing sleep, short-term memory/concentration problems, muscle pain, joint pain without swelling or redness, tender lymph nodes in the neck or armpit, sore throat or headaches [1,2]. Several cognitive behavioural models of CFS exist, which try to explain the perpetuation of symptoms in CFS patients [3–6]. All start with a period of severe fatigue that many patients, rightfully or not, attribute to a physical illness. In order to recover, patients often rest and become less active. Most models assume that because of this inactivity, patients' physical condition will decline and they will become increasingly sensitive to fatigue. In one of these models, that of Vercoulen

et al. [7], a low level of physical activity, a low sense of control over fatigue, and a high level of focusing on symptoms explain the perpetuation of fatigue and impairment. The low level of physical activity is related to somatic attributions, as patients may avoid physical activity when they attribute their symptoms to a somatic illness. Although there are more recent models that also include physiological and social factors [8], this is still the only model that simultaneously tested the influence of several perpetuating factors. Based on these models, several protocols for CBT were developed [9–12] that lead to a significant reduction of fatigue and impairment [13,14]. Although protocols differ, they all encompass a stepwise increase in physical activity and challenging of dysfunctional fatigue-related beliefs.

Recently, Wiborg et al. developed a comprehensive treatment model of CBT for CFS [15], based on the model of Vercoulen et al. [7]. For their analyses they used data from previous randomised controlled trials (RCTs) testing the efficacy of CBT for CFS. Wiborg et al. first tested for each variable in the model of Vercoulen whether it was a mediator of CBT for CFS, i.e. whether it changed more in patients receiving CBT than in the control group and whether it indirectly explained (part of) the effect of treatment on symptom change. Two adaptations were made to the original variables: somatic attributions were not analysed,

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as previous research had shown that somatic attributions do not change during treatment [10], so they could never be a mediator of CBT; and perceived problems with activity were analysed, rather than objective activity assessed with actigraphy, as previous research had shown that objective activity or physical fitness do not mediate the effect of CBT for CFS [16] and other behavioural interventions for chronic fatigue [17,18]. In the final model, the decrease in fatigue is explained by an increased sense of control over fatigue, an increase in perceived activity, and improved physical functioning.

There are three limitations to the model of Wiborg et al. First, the model relied only on measurements before and after therapy and did not study the process of change during therapy. We therefore do not know whether changes in mediating variables indeed precede changes in fatigue. This makes it impossible to draw causal conclusions. Furthermore, temporary changes, which may catalyse other change processes, will go unnoticed. For example, a permanent change in objective activity does not mediate the treatment effect, but a temporary increase in activity might lead to changes in cognitions, which then lead to a decrease in fatigue. Second, focusing on symptoms was measured with the subscale 'somatic complaints' of the Symptom Checklist 90. As the authors argued themselves, this questionnaire may have been unsuitable. Third, the model was tested in an RCT of a minimal intervention based on CBT for CFS [19]. Patients received a self-help booklet explaining the different components of CBT. In addition, they had regular email contact with a therapist. Tummers et al. showed that fatigue and impairment decrease significantly when patients follow additional CBT after such a minimal intervention [20]. So individual CBT may have a more complex mechanism of change, i.e. it may target more processes, than the minimal intervention Wiborg et al. tested.

We built on the treatment model of Wiborg et al. by studying the change in different process variables during individual CBT. In Fig. 1 all proposed process variables are depicted. First of all, we selected the variables of the model of Wiborg et al., i.e. sense of control over fatigue, perceived activity and self-reported physical functioning. We added focusing on symptoms because this variable mediated the effect of CBT for CFS in an earlier RCT [21] and may have been measured inadequately in the study of Wiborg et al. These four variables had thus been proven to mediate the effect of CBT for CFS in formal mediation analyses of RCTs. Although objective activity was previously discarded as a mediator of CBT for CFS [16], we included this variable because a temporary change in objective activity might elicit other changes.

## Methods

### Patients

Consecutively referred patients who started CBT at our tertiary CFS specialist care centre between April 2008 and September 2010 were eligible to participate if they:

- Met the criteria for CFS as stated by the US Centers for Disease Control and Prevention [1,2], i.e. severe fatigue, severe functional

impairment and experiencing at least 4 out of the eight accompanying symptoms of the Fukuda criteria. Severe fatigue was defined as a score of  $\geq 35$  on the Checklist Individual Strength (CIS) subscale fatigue severity [22], and severe functional impairment was defined as a total score  $\geq 700$  on the Sickness Impact Profile (SIP) [23–26]. If a consultant or primary care physician had not ruled out any somatic disorder that excludes the diagnosis of CFS following the Fukuda criteria [1], patients first received a standard medical examination at the outpatient clinic of our department of internal medicine.

- Were between 18 and 65 years old
- Were able to read and write Dutch.

Patients were excluded if:

- They were currently applying for a disability claim until their application was completed, as this has previously been found to negatively influence treatment outcome [27].

The study was carried out in accordance with The Code of Ethics of the World Medical Association (Declaration of Helsinki) for experiments involving humans <http://www.wma.net/en/30publications/10policies/b3/index.html>; uniform requirements for manuscripts submitted to biomedical journals <http://www.icmje.org>. It was approved by the ethical committee of the Radboud University Nijmegen Medical Centre. All participants gave written informed consent before participation.

### CBT protocol

According to the protocol of CBT for CFS used in this study [9,28] the therapy needs approximately 12 one-hour sessions during 6 months. Actually the duration of therapy is jointly determined by the patient and therapist. At the start of therapy patients define concrete personal goals, usually including resumption of work, hobbies and other activities that imply recovery for the patient. Recovery, i.e. no longer being severely fatigued and impaired, is according to this protocol the highest goal to strive for in therapy. Patients are asked to regulate bedtimes and stop sleeping during the day, to stop possible disruption of the circadian rhythm. During the sessions, the therapist challenges non-accepting and catastrophising thoughts that inhibit adequate coping, and patients learn to distract their attention from their fatigue. Two groups of patients are discerned: Relatively active patients characterised by bursts of activity followed by prolonged periods of rest, and low active patients, who score below the mean of CFS patients on at least 90% of the days during actigraphic measurement [29]. Low active patients start with a graded activity programme immediately after the initial cognitive interventions. Relatively active patients first spread their activities more evenly across the day, after which they start the graded activity programme. This activity programme consists of daily walking or cycling, which is gradually increased. The increase in activity is not determined by the level of symptoms, but is time contingent. When patients succeed in increasing their physical activity, they start to increase social and mental activities. In the last phase of therapy, patients work systematically towards reaching their goals and experiment with fluctuating their bedtimes and activity level again. They are encouraged to perceive feelings of fatigue as a normal part of an active and healthy life and stop labelling themselves as a CFS patient. In total 12 therapists participated in our study, who had been thoroughly trained in the protocol of CBT for CFS and received frequent intervision and supervision. We did not use therapy aids, such as books or handouts and phone support between sessions was only provided when needed urgently. Costs of treatment were covered by standard medical insurance.

### Measurements

Besides the regular pre- and post-therapy measurements we planned three interim measurements at 6, 12 and 18 weeks after the start of therapy. Patients received the questionnaires from the researcher and

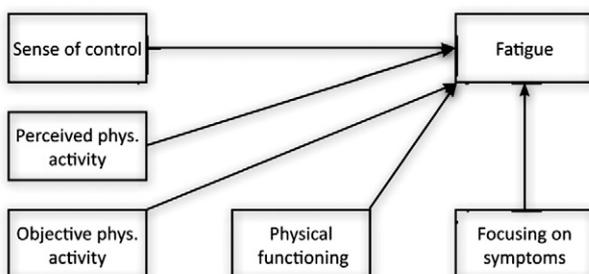


Fig. 1. Potential process variables that we tested, based on the models of Wiborg [15] and Vercoulen [30].

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