



## Cognitive behavior therapy in patients with chronic fatigue syndrome: The role of illness acceptance and neuroticism

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### ABSTRACT

**Objective:** Increasing the quality of life (QoL) of patients with chronic fatigue is challenging because recovery is seldom achieved. Therefore, it is important to identify processes that improve QoL. This study examined the extent of improvement related to cognitive behavior group therapy (CBT), and whether improvement is affected by initial levels of acceptance and neuroticism.

**Methods:** Eighty CFS patients followed CBT, and self-reported (pre–post design) on mental and physical QoL (MQoL and PQoL), fatigue, acceptance, and neuroticism. The extent of improvement was analyzed using t-tests, effect sizes, and clinically significant change criteria. Whether acceptance and neuroticism at baseline predicted changes was analyzed by means of correlation and regression analyses.

**Results:** Significant improvement was found for all variables. The effect size for MQoL and PQoL was small; for acceptance and fatigue, effect size was moderate. About 20% (MQoL) to 40% (fatigue) of the participants clinically improved.

Pre-treatment level of acceptance was negatively correlated with changes in MQoL, not with PQoL changes. Neuroticism pre-treatment was positively related with MQoL changes. Regression analysis showed an effect of acceptance on changes in MQoL beyond the effect of neuroticism.

**Conclusions:** Although CBT is an evidence-based treatment, the sizes of the effects are often small regarding QoL. Our study also revealed small effect sizes. Our study showed that patient characteristics at baseline were significantly associated with MQoL outcome; indicating that CFS patients with high neuroticism or with a low acceptance show more improvement in MQoL. We propose to specifically target acceptance and neuroticism before treatment in order to maximize clinical relevance.

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### Introduction

Chronic fatigue syndrome (CFS) is a complex syndrome with severe disabling fatigue lasting for at least 6 months as the major criterion according to the Centre for Disease Control [1]. The precise medical pathophysiology remains unknown, and many researchers adopt a bio-psycho-social account for this ‘medically unexplained syndrome’, acknowledging the importance of complex and dynamic interactions between biological, psychological and social factors. Within this account, cognitive behavioral models have become increasingly popular [2–5]. These models propose a set of predisposing factors (e.g., genetics, personality characteristics, and life events), precipitating factors (e.g., physiological factors and general distress) and perpetuating factors (e.g., physiological, cognitive, behavioral,

and social reactions) that each may contribute to the development and maintenance of CFS [3–8].

Cognitive behavioral models are equally well used to deliver treatments for CFS. Most often cognitive-behavioral therapy (CBT) for CFS targets cognitive and behavioral perpetuating factors such as the imbalance between rest and activity, and the belief that they have to be perfect in every situation, potentially resulting in ignoring their physical limits. Research has shown that CBT improves physical functioning and fatigue reduction immediately and some time after treatment [9,10]. Nevertheless, complete recovery is uncommon.

A recent meta-analytical study of Castell and colleagues shows an overall effect size for CBT of 0.33, which is small according to Cohen's recommendations [10,11]. This research group suggested that the variability in fatigue outcomes in CBT reflects the existence of moderating variables and examined illness characteristics and treatment characteristics. Regarding *illness characteristics*, illness duration does not affect the outcome of CBT in CFS. Regarding *treatment characteristics*, total duration of CBT (in hours) showed a positive influence on the outcome. No evidence was found that the treatment format (group or individual) and treatment duration (weeks) affected the

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effect size of CBT [10]. Although group programs are often preferred because of the cost efficacy and the involvement of peer support, support groups without therapy do not yield similar outcome results as CBT [12].

Other studies indicate that *patient characteristics* also matter: CBT effect increases when patients are less focused on their symptoms and are less anxious about it [13,14]. Until now the role of illness acceptance in CBT has received little attention [15].

Illness acceptance is defined as “recognizing the need to adapt to a chronic illness while perceiving the ability to tolerate the unpredictable, and handle its adverse consequences” [16]. This way of coping with adversity is more and more acknowledged to be related to a good adjustment to chronic illness [17–22]. Its function is also well-articulated in self-regulatory models of coping [23–25]. One example of such a model is the ‘dual-process model of coping’ of Brandtstädter and colleagues [26,27], which distinguishes between two complementary coping strategies: accommodative coping and assimilative coping. ‘Assimilative coping’ is characterized by active attempts to control the stressor and solve the problem, in order to continue with the pursuit of one’s life goals. When a problem remains insoluble and blocks life goals, stress increases and a transition from assimilative to accommodative coping may be required. In accommodative coping “the structure of individual cognitions and valuations is modified to make the given situation appear less negative or more acceptable” that leads to the disengagement from the blocked goals, and goal adjustment or reengagement with feasible goals [26]. Acceptance of adverse consequences and uncontrollability of an insoluble problem is often considered as a key process in accommodative coping [16,28]. Chronic illness, such as CFS, may be considered as a problem that cannot (yet) be cured or solved, and where an accommodative coping strategy and illness acceptance are to be preferred. In line with this view, cross-sectional studies indicate that acceptance plays a role in adjustment to chronic illnesses, such as CFS and that acceptance has been found to be associated with a better mental health-related quality of life (MQoL) [17,27,29–31]. Of further interest are the results of Brooks and colleagues, who found that CBT for CFS resulted in an increase of acceptance, and that lack of acceptance was associated with fatigue and physical functioning [15]. In our study, we are interested whether acceptance before the start of CBT predicts the effects of treatment regarding health-related quality of life and fatigue.

Another patient characteristic which we will examine in relation to CBT treatment is personality. Personality traits are related to how individuals cope with problems [32]. In particular the trait ‘neuroticism’, which is characterized as the degree of emotional instability, associated with a tendency to experience negative emotions, vulnerability for stress and for psychopathology, may be relevant [33]. First, neuroticism is presumed to be one of the predisposing factors of CFS [4,5,34] in biopsychosocial accounts. Second, there is preliminary evidence that neuroticism negatively influences illness acceptance and mental wellbeing in CFS [31]. In our study, therefore, we wanted to examine whether neuroticism before treatment negatively influences the effects of CBT.

Next to fatigue, quality of life (QoL) should be a substantial outcome parameter to evaluate the condition of patients after treatment. QoL often has two dimensions: a mental health quality of life (MQoL) and a physical health quality of life (PQoL). Increasing QoL in patients with CFS is a challenge because recovery is difficult to achieve. Research shows that the QoL is lower in CFS patients compared with other chronic ill and healthy control groups [35–37]. One of the possible reasons is that overall patients with CFS score higher on neuroticism, which is related to a more negative perception of symptoms, disability, and health [38,39]. Another reason might be that patients with CFS have difficulties with accepting the fatigue and its devastating consequences, especially because CFS is regarded as a medically unexplained illness [8]. Although it has already been shown that non-accepting cognitions seem to lead to maladaptive activity patterns in patients with CFS which results in increased fatigue, frustration and a

negative QoL [30,31,40,41], more research is needed to highlight the importance of acceptance for adjusting to a life with CFS.

In sum, this study examined the extent of improvement related to cognitive behavior group therapy (CBT) on MQoL, PQoL, fatigue and acceptance, using a pre–post design without no-treatment control group, and, of most importance to this study, whether the observed improvement in outcomes is affected by initial levels of acceptance and neuroticism. We will use three methods (statistical, practical, and clinical) to evaluate the pre–post treatment changes in mental and physical health-related QoL, fatigue and acceptance.

## Method

### Participants

Patients with CFS from the general internal medicine outpatient clinic of the Ghent University Hospital were invited to participate in the study in the period 2009–2011. They experienced group CBT over a period of 6 months. The pre-treatment data were collected during a psychological assessment phase, which was a part of a multidisciplinary diagnostic procedure. In this procedure psychological assessment was the second examination after the diagnostic investigation by the internist. The psychological assessment was followed by a psychiatric assessment and a multidisciplinary patient discussion, in which the diagnosis of CFS according to Fukuda et al.’s criteria [1] is made and treatment modalities are discussed. Between the baseline measurement and the start of CBT-treatment there was a period of approximately 4–6 months. The post-treatment data were collected at the end of the treatment. The duration of the treatment was 6 months. There was a mean of 12.4 months between pre- and post-treatment measurement. The number of group members ranged from 8 to 12. All patients provided informed consent, and the study was approved by the local ethics committee. Inclusion criteria of the study were: knowledge of Dutch language (in order to fill-in the Dutch questionnaires), age (minimum of 18 years old), and a diagnosis of CFS according to the CDC criteria [1] with a strict exclusion for medical (internal and psychiatric) diagnoses that could explain the fatigue symptoms. The data from the pre-treatment questionnaires of the patients who did not complete the treatment program were excluded, which resulted in 80 patients (73 women and 7 men). Various reasons were given for drop-out including the following: impossible combination of work and therapy, other medical diagnoses received during treatment, and family circumstances.

The group CBT was conducted by four psychologists trained by a cognitive behavioral therapist for this program. We chose a group CBT program because of cost efficacy and the putative value of peer support. CBT aimed at increasing functioning, and its objective and content are comparable with manuals of other CBT trials [9,12]. The treatment program consisted of twelve, 2-hour sessions, and a session was held every 2 weeks. The program included stress management (psycho-education on stress and fatigue and a relaxation therapy according to the Jacobson technique), gradual activity management (in the first phase patients are learning to find a balance between rest and activity by activity planning, in a second phase, activity was gradually built up), sleep management (psycho-education on sleep hygiene and sleep disorders, and stimulating a regular sleep pattern), and cognitive therapy (identifying and challenging negative cognitions about fatigue, and cognitive restructuring) [9]. No specific interventions regarding acceptance were included.

### Measures

In this study, we used self-report questionnaires to assess the following variables: mental and physical QoL, fatigue severity, acceptance, and neuroticism. All participants completed the questionnaires described below.

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