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Do changes in illness perceptions, physical activity, and behavioural regulation influence fatigue severity and health-related outcomes in CFS patients?

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ABSTRACT

Objective: Examine to what extent changes in cognitions and changes in physical activity and behavioural regulation patterns influence fatigue severity, physical symptoms, and physical and psychological functioning of patients suffering from Chronic Fatigue Syndrome (CFS) at follow-up.
Methods: The present study is an observational longitudinal study with a 12-month follow-up. A total of 144 CFS patients participated both at baseline and at follow-up. Four separate hierarchical regression analyses were conducted with fatigue, physical symptoms, physical functioning and psychological functioning at follow-up as the dependent variables, and (changes in) illness perceptions and behavioural regulation patterns (all-or-nothing and limiting behaviour) as the independent variables. Data were collected making use of self-report questionnaires.
Results: Increased Consequence and Identity beliefs over time, as well as increases in all-or-nothing behaviour predicted higher fatigue severity at follow-up. Both number and severity of physical symptoms and psychological functioning at follow-up were only determined by changes in illness perceptions, with increased Consequence beliefs influencing both outcomes, and increased Timeline beliefs only determining physical symptoms. Physical functioning at follow-up was predicted by changes in illness perceptions as well as increased levels of both all-or-nothing and limiting behaviour.
Conclusion: The findings point at a differential pattern of associations between changes in illness perceptions and behaviour regulation patterns on the one hand, and patient outcomes on the other hand. Whereas illness perceptions significantly contribute to each of the outcomes, behaviour regulation patterns contribute only to fatigue severity and physical functioning.

1. Introduction

Chronic Fatigue Syndrome (CFS) is characterized by medically unexplained fatigue of at least six month duration, the fatigue has to be severe, disabling and lead to a significant reduction in level of occupational, personal and/or social functioning. CFS is diagnosed on the basis of the Oxford criteria [1] or the more restrictive Center for Disease Control (CDC) criteria [2]. According to the CDC criteria, the patient must also have reported at least four (out of eight) other somatic symptoms in addition to fatigue.

The prevalence of CFS ranges from 0.6% to 2.5%, depending on the diagnostic criteria used, the setting (general population, primary, secondary, or tertiary care) and the country in which the studies were carried out [3,4]. CFS seems to affect mainly young adults from 20 to 40 years old, the prevalence is two to three times higher in women, and seems to be comparable across socio-economic groups [4]. The prognosis of CFS is generally poor. In their review, Joyce and colleagues [5] state that < 10% of patients return to premorbid levels of functioning, a figure that was confirmed by a 3-year follow-up study [6]. While full recovery rates are low, there is a broader range in improvement rates among studies ranging from 6 to 63% [5].

Theoretical frameworks for CFS usually distinguish between factors that may render people more vulnerable to the development of CFS (predisposing factors), factors that may trigger CFS (precipitating factors) and factors that maintain CFS and impede recovery (perpetuating factors) [7,8]. The perpetuating factors are considered to be most important in view of the development of interventions as they may be responsible for the maintenance and, eventually, worsening of fatigue symptoms.

Existing models of perpetuating factors usually emphasize the role of psychological processes, especially cognitions and behaviours, in

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maintaining CFS [9,10] . These factors coincide with the key ingredients of the two treatment modalities that are considered to be efficacious for CFS according to the UK National Institute of Health and Clinical Excellence (NICE) guidelines on CFS [11] and to a number of meta-analyses on the subject [12–15]. These treatment modalities are: (a) Cognitive Behaviour Therapy (CBT), focusing on challenging dysfunctional cognitions related to fatigue/CFS, gradually increasing physical activity behaviour, and establishing a good activity/rest balance [16], and (b) Graded Exercise Training (GET) solely focusing on physical activity behaviour [13].

Recently, the question has been raised to what extent cognitions and behaviours mediate the effect of psychological and behavioural interventions (such as CBT and GET) on fatigue severity and patient functioning. On the basis of a re-analysis of three Randomized Controlled Trials (RCTs), examining the role of physical activity as a mediator of the effect of CBT on fatigue severity [17], it was demonstrated that changes in physical activity were not related to changes in fatigue. A similar result was found in a study by Heins et al. [18]. Another study [19] investigated whether the effect of CBT on fatigue and functional impairment was mediated by a cognitive factor (focusing on fatigue) and/or a behavioural factor (activity avoidance). A decreased tendency to focus on fatigue, but not a decreased tendency to avoid activity, was found to be a mediator of the effect of CBT on patient outcomes. Many studies therefore suggest that the efficacy of CBT for CFS is mediated by changes in cognitions and illness beliefs [17–20]. On the basis of these, but also earlier studies pointing out that cognitive dimensions were predictors of treatment effects [21,22], Knoop et al. [23] concluded that cognitions play a pivotal role in the maintenance of symptoms. More specifically, these authors' hypothesis is that an increase in physical activity, which is an important aspect of CBT, leads patients to change their perception of fatigue (with fatigue again becoming a normal sensation) and of the relation between fatigue and physical activity ("Despite my fatigue, I can be physically active."), which in turn has a positive influence upon fatigue-related outcomes. The results of a more recent study, looking into the mechanisms of change underlying CBT in CFS [24], seem to be in line with this hypothesis. More specifically, it was found that a path model where cognition acts as a mediator between behaviour and fatigue was statistically superior to a model where behaviour acts as a mediator between cognitions and fatigue.

The question is, however, whether the above mentioned hypothesis also applies to GET, where the focus of the intervention is solely on a gradual increase in level of physical activity. One study evaluating the effect of GET found that, within the intervention group, changes in illness perceptions, but not changes in fitness, were related to less fatigue and improved functioning after treatment [25]. Another study, evaluating a pragmatic rehabilitation intervention focusing upon gradual increases in level of physical activity, found however that both reductions in limiting behaviour and reductions in catastrophizing mediated treatment effects on fatigue [26].

Although the results of the above-mentioned intervention studies suggest that cognitive factors play a more central role than behavioural factors in predicting post-treatment fatigue and functioning in CFS patients, little is known about the role of cognitive and behavioural factors in the natural course of (long-standing) CFS. That is why we were interested in this study in examining if, and to what extent, changes in cognitions and behaviours over time predict changes in important patient outcomes. The research question of this study is therefore: "To what extent do changes in cognitions about fatigue (i.e. illness perceptions) and changes in behavioural factors (i.e. level of physical activity and behaviour regulation patterns) influence changes in fatigue severity, number and severity of physical symptoms, and (physical and emotional) health-related quality of life of CFS patients over a one-year follow-up period?"

2. Methods

2.1. Design

The present study is an observational longitudinal study with a 12 month follow-up. All patients participating in the study gave their written informed consent. Approval from the Ethical Committee of the Institute of Psychology at Leiden was obtained (20-1-2010/CEP255).

2.2. Sample

The participants for the study were recruited from a large Dutch patient organization. Initially an informational email was sent to 1800 members of the organization, containing information on the rationale and aim of the study. Three hundred and eighteen patients were interested in participating in the study; 261 patients (82%) filled out the baseline questionnaires (T1). After baseline measurement, 35 patients (13.4%) were excluded because they reported to have a chronic disease that could account for their fatigue and/or because they received psychological or psychiatric treatment for a severe psychiatric disorder. To check whether all patients in our sample fulfilled the CDC criteria for CFS [2], they filled out a CDC-based checklist for CFS [27]. As a result, 12 patients were excluded (4.5%). The number of patients at T1 was thus reduced to 214. At one-year follow-up, 144 patients (67%) filled out the questionnaires a second time (T2). No significant differences were found between the patients that participated only at T1 and the patients that participated at both time points for age, gender, and illness duration.

2.3. Measures

2.3.1. Independent variables

Illness perceptions were measured using the validated Dutch version of the Brief Illness Perception Questionnaire (Brief IPQ-DLV) measuring (perceived) consequences, timeline, identity, personal control, treatment control, coherence, emotional representation, and cause [28]. Cause was not measured in this study. Emotional Representation is constructed by summing the responses, ranging from 1 to 10, on two items, Concern and Mood. All other dimensions are measured with a single item and scored on a scale from 1 to 10. For the subscales consequences, timeline, identity and emotional representation, higher scores represent more negative illness perceptions (e.g. more consequences or a longer timeline). For the subscales personal control, treatment control and coherence, higher scores represent more positive illness perceptions (e.g. more personal control or more treatment control). The Brief IPQ was shown to have good reliability and validity [28,29]. Both the original IPQ [30] and the brief IPQ discriminate well between patients suffering from different chronic conditions, including CFS [31].

Physical activity was determined with the Short Questionnaire to Assess Health-Enhancing Physical Activity (SQUASH) [32]. Patients were asked whether they engaged in physical activity such as walking, biking or sports and what kind of physical activity they performed. Patients were also asked to specify the frequency (days per week) and duration (hours and/or minutes per day) of that physical activity. For every specified physical activity the frequency (days) was multiplied by the duration (minutes). The total score for physical activity was calculated by summing the amount of minutes for all physical activities specified. Higher scores indicated more minutes of physical activity per week. The SQUASH has been found to be a reliable and valid questionnaire, and has been used in adults with chronic conditions, including CFS [33,34].

Behaviour regulation patterns were assessed with the *All-or-nothing* and *Limiting behaviour* scales from The Behavioural Responses to Illness Questionnaire (BRIQ) [35]. The first dimension assesses the "boom and bust pattern" typically observed in CFS and the second dimension assesses the excessive rest that patients take due to their fatigue problems.