



## Differences in physical functioning between relatively active and passive patients with Chronic Fatigue Syndrome

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### ABSTRACT

**Objective:** According to the Cognitive behavioral therapy (CBT) protocol for patients with Chronic Fatigue Syndrome (CFS), therapists are advised to categorize patients in relatively active and passive patients. However, evidence to support the differences in physical functioning between these subgroups is limited. Using the baseline data from a multicentre randomized controlled trial (FatiGo), the differences in actual and perceived physical functioning between active and passive patients with CFS were evaluated.

**Methods:** Sixty patients, who received CBT during the FatiGo trial were included. Based on the expert opinion and using the definitions of subgroups defined in the CBT protocols, the therapist categorized the patient. Data from an activity monitor was used to calculate actual physical functioning, physical activity, daily uptime, activity fluctuations and duration of rest during daily life. Perceived physical functioning was assessed by measuring physical activity, physical functioning and functional impairment with the Checklist Individual Strength, Short Form-36 and Sickness-Impact Profile 8.

**Results:** Relatively active patients have a significantly higher daily uptime and show significantly less fluctuations in activities between days. Passive patients experience a significantly lower level of physical functioning and feel more functionally impaired in their mobility. However, no significant differences were found in the other actual or perceived physical functioning indices.

**Conclusions:** A clear difference in actual and perceived physical functioning between relatively active and passive patients with CFS as judged by their therapists could not be found. Future research is needed to form a consensus on how to categorize subgroups of patients with CFS.

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### Introduction

Chronic Fatigue Syndrome (CFS) is a condition characterized by persistent fatigue, which is not the result of an identifiable organic disease or ongoing exertion and lasts for at least six months. Rest does not alleviate the fatigue. CFS often leads to a substantial limitation in occupational, educational, social and personal activities [1].

Although results are conflicting, several studies found the actual as well as the perceived physical functioning to be lower in patients with CFS compared to healthy, age matched controls [2–5]. A possible explanation for the conflicting results in physical functioning might

be the large variations in actual and perceived physical functioning within the population of patients with CFS. The study of van der Werf [2] investigated the differences in perceived physical functioning between subgroups of patients. The average daily physical activity level, measured by the actometer of the total group of patients, was used as reference value to form subgroups. The number of days below or above this reference value determined in which subgroup a patient was categorized. Results showed that two subgroups could be identified. A group of pervasively passive patients, reporting less daily activities and perceive more limitations in daily life functioning compared to the other subgroup of relatively active patients. In addition, Prins et al. [6], who studied the effectiveness of Cognitive Behavioral Therapy (CBT) in patients with CFS, found that the individual level of daily physical activity predicted the treatment outcome. Passive patients showed hardly any improvement after CBT. Therefore CBT protocols were adjusted for subgroups of patients (passive patients versus relatively active patients) in order to increase effectiveness of the CBT. In the Netherlands, these tailored CBT protocols for relatively active

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and passive patients are used frequently. In these clinical diagnostic and therapeutic protocols [6,7], relatively active patients are assumed to be more physically active, spend less time resting and show infrequent bursts of activity followed by extreme exhaustion during the day and between days (high level of fluctuations of activities). Passive patients with CFS are assumed to stay at home more often, not to walk long distances and lie down most of the day [6,7]. Nowadays CBT often incorporates a gradual increase in physical activities. In the CBT protocol for the passive patients, physical activities will be increased from the beginning of therapy. The relatively active patient is first taught to practice at a baseline activity level without bursts of activity in order to stabilize the level of activities and prevent extreme exhaustion. After stabilization has been reached, activities will be increased gradually. According to Prins et al. [8] passive patients do not recover when they receive the CBT protocol for active patients. Therefore it is important to categorize patients correctly, as differences in physical functioning guides treatment content. Experts in CBT advise to categorize patients with the use of an actometer [6,7]. In clinical practice an actometer or other actual activity monitoring system is usually not available because they are too expensive, time-consuming, complex to analyze and difficult to interpret. Questionnaires on daily physical activity are used instead of the actometer but are still lacking validity [9]. Which method is the most valid for categorization is still unclear and needs further investigation. Currently therapists categorize patients using the definitions in the CBT protocol [6,7]. Although categorization of patients is often used in clinical practice, the assumed differences in physical functioning between relatively active and passive patients, as described in clinical protocols, have never been confirmed by measuring the actual daily life activities using an activity monitor. In patients with chronic low back pain (CLBP), it was found that a subgroup of avoiders, who seem to closely resemble the passive patients, had significantly higher disability levels, a lower perceived daily life activity level, and lower daily uptime compared to a subgroup of persisters [10]. However, no differences in the actual daily life activity level and fluctuations of activities over time could be found. In the CBT protocols for CFS [6,7] experts on CBT state that a patient's perception on physical activity is often distorted by cognitions regarding activity resulting in a discrepancy between what people say and what they actually do. Therefore, it is important to get insight in the patients' actual level of physical functioning as well as their perceived level of physical functioning, in both subgroups.

Hence the first aim of the present study is to evaluate the differences in actual physical functioning between subgroups, i.e. whether passive patients with CFS have a significantly lower actual total physical activity level, spend less time awake and out of bed (daily uptime), spend more time resting, and show less activity fluctuations compared to relatively active patients with CFS. The expert opinion, as this is the most commonly used form, will be used to categorize the patient. A second aim is to evaluate the differences in perceived physical functioning between subgroups, i.e. whether passive patients are significantly more impaired and have a lower perceived daily life activity level compared to relatively active patients with CFS.

## Methods

This study is part of a multicentre randomized controlled trial (FatiGo) in which the effectiveness of two treatment approaches, multidisciplinary rehabilitation treatment (MRT) and CBT, are compared in patients with CFS [11]. Primary aim of the FatiGo trial is to compare the effectiveness of both outpatient rehabilitation treatment approaches on fatigue severity and quality of life in patients with CFS. The study protocol has been approved by the Research Ethics Committee of Rotterdam in the Netherlands (number 2008/22). Trial-registration: Current Controlled Trials ISRCTN77567702. In order to evaluate the difference in physical functioning between relatively active and passive patients with CFS, baseline data from 60 patients with

CFS who were randomized CBT between 1 December 2008 and 28 January 2011 were analyzed.

## Participants

The patients with CFS referred to Revant Rehabilitation Centre Breda, Rehabilitation Centre Blixembosch in Eindhoven, Reade Rehabilitation Centre in Amsterdam and Adelante Rehabilitation Centre in Hoensbroek between November 2008 and January 2011 were asked to participate in the trial. Patients were included if the following criteria were met: (1) CDC-94 criteria for CFS, (2) The subscale on severity of fatigue of the Checklist Individual Strength should be higher or equal to 40, (3) participant agreed to participate in a treatment aimed at changing behavior, (4) age between 18 and 60 years, (5) able to speak, understand and write the Dutch language. Patients with any other medical condition which can explain the presence of chronic fatigue, a psychotic, major or bipolar depressive disorder, dementia, anorexia or bulimia nervosa, alcohol and/or drug abuse, severe obesity, pregnancy, previous or current CBT or MRT for their CFS or living more than 1 h travelling time away from the nearest participating rehabilitation centre, were excluded from the study. Patients should be able to attend therapy for at least three half days a week. A physician in rehabilitation medicine checked the in- and exclusion criteria. All patients signed the informed consent form.

## Procedure

After inclusion, baseline assessment was performed and patients were asked to fill in the Checklist Individual Strength (CIS) [12,13], the Sickness Impact Profile 8 (SIP8) [14,15] and Short Form-36 (SF-36) [16]. The research assistant instructed the patient to wear the activity monitor on the right upper arm over the triceps muscle during seven consecutive days. The different outcomes variables for actual and perceived physical functioning are shown in Table 1. After baseline assessment, patients were randomly assigned to CBT or MRT. Because the CBT protocol is different for passive and relatively active patients with CFS, the CBT therapists were trained before the trial started to categorize the patients. Only patients from the CBT group were included in the analysis of the present study, because in MRT, the protocol is not different for subgroups of patients, and patients were therefore, not categorized by their therapists. Only data from baseline assessment of the FatiGo trial [11] were used in the present study.

## Classification of patients

During two to three intake sessions, the CBT therapist categorized the patient by questioning the patient about his/her daily activities, using the week list of activities, which the patient had filled in during the week he or she was wearing the activity monitor. Furthermore, the CBT therapists had access to the results of the baseline questionnaires and they were free to use the information in their judgement when categorizing. None of the questionnaires had cut-off scores for categorization of patients with CFS into subgroups. The therapists had access to the results of the questionnaires on depression and anxiety (Hospital Anxiety and Depression Scale) [17], quality of life

**Table 1**

Outcome variables of actual and perceived physical functioning as used in the present study.

Actual (activity monitor)	Perceived (self report questionnaire)
Physical activity (PA)	Physical activity, CIS activity
Daily uptime	Physical functioning, SF-36
Duration of rest	Functional impairment, SIP8
Fluctuations between days (RMS-day)	Physical impairment, mobility (SIP mobility)
Fluctuations within days (RMS-15)	Physical impairment, walking (SIP walking)

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