



The role of acceptance in chronic fatigue syndrome

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ABSTRACT

Objective: In this paper we consider the role that acceptance plays in fatigue and physical and social functioning. We predicted that lack of acceptance would be positively correlated with fatigue and impairment in functioning; that there would be a significant relationship between perfectionism and acceptance; and cognitive behavioural therapy (CBT) would increase acceptance.

Methods: Two hundred and fifty nine patients with chronic fatigue syndrome (CFS) completed questionnaires measuring fatigue, physical functioning, work and social adjustment, lack of acceptance, perfectionism and depression. Ninety consecutive attenders received a course of CBT and completed further questionnaires at discharge and 3 months post-treatment. Correlations and multiple hierarchical regressions were used to determine relationships between acceptance, perfectionism and clinical outcome variables.

Results: At baseline, lack of acceptance was the key factor associated with impaired physical functioning and work and social adjustment. Lack of acceptance and doubts about actions were associated with fatigue in a multiple regression analysis. At discharge and follow-up patients showed significantly increased acceptance, as well as reduced Concern over Mistakes, less fatigue and impairment of physical functioning, and improved work and social adjustment.

Conclusion: This is the first study to our knowledge which shows a change in acceptance after CBT and a relationship between acceptance and perfectionism. Acceptance may be an important factor to consider within treatments for CFS.

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Introduction

Chronic fatigue syndrome

Chronic fatigue syndrome (CFS) is a disorder defined by persistent severe fatigue, unrelated to exertion and not relieved by rest, lasting at least 6 months [1,2]. People with CFS generally experience muscle and joint pain; difficulties in cognitive and psychological functioning; disturbed sleep; and mental and physical exhaustion. These symptoms are associated with impaired physical and social functioning.

The present study considers CFS in the context of a cognitive behavioural approach, which focuses on how cognitive, behavioural, physiological and social factors interact to perpetuate the condition [3]. One aspect of this model suggests that unhelpful beliefs or thinking patterns such as catastrophising lead to a reduction in activity which worsens symptoms of CFS and creates a 'vicious circle' perpetuating fatigue and disability. It has been suggested [4] that the desire to meet responsibilities and high standards may be hindered by symptoms of fatigue, and the perceptions of actual or feared failure may then exacerbate the symptoms and cause further distress, thus creating

another 'vicious circle'. This desire to meet high standards may well be an aspect of perfectionism, which will be discussed further below.

One of the main interventions for CFS is Cognitive Behaviour Therapy (referred to hereafter as CBT), a collaborative treatment in which patient and therapist work together using a variety of techniques to improve fatigue and functioning. Therapy is adapted to the needs of the individual and may include: pacing (establishing a consistent pattern of activity and rest); gradual increase in activity levels; sleep management; and addressing unhelpful thinking patterns including perfectionism. Systematic reviews have shown CBT to be effective in improving functioning and reducing fatigue in CFS patients [5]. CBT, along with Graded Exercise Therapy, has also been shown in a non randomised trial to significantly improve "action-proneness" (cognitive and behavioural tendency towards direct action), although not to pre-morbid levels [6].

Acceptance

Research on patients with chronic pain has suggested that attempting to control pain which is uncontrollable (lack of acceptance) is associated with distress and frustration [7,8], reduced physical functioning [9], higher pain identity and more serious perceived consequences [10]. Lack of acceptance has also been shown to be inversely related to the ability to undergo positive, personal change for better health and wellbeing [11]. Conversely, increased acceptance –

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giving up attempts to control pain – has been associated with less psychological distress and better wellbeing and adjustment [9,12].

Despite the wealth of research into acceptance and chronic pain, the concept of acceptance in relation to chronic fatigue is discussed much less. One study which does consider the relationship between acceptance and CFS symptoms found that higher levels of acceptance were associated with greater psychological wellbeing and less distress in patients with CFS [13]. Another study, using an imagery paradigm, found that 'acceptance imagery' was associated with less hyperventilation in CFS patients than imagery of hostile resistance [14]. Analysis of qualitative interviews with CFS patients has suggested that acceptance may be a mechanism for integration of CFS as part of a new identity with adjusted values and re-conceptualised goals, which helps to restore a sense of personal control, self-esteem and self-worth [15]. There is however a gap in this literature regarding the relationship between acceptance and *disability* in sufferers of chronic illnesses.

Perfectionism

It has been suggested [16] that perfectionism comprises two factors – 'personal standards' (striving to achieve high standards) and 'evaluative concerns' (self-doubt and criticism). It has also been argued [17] that there are two types of perfectionism – 'positive' and 'negative'. The role of perfectionism in the aetiology of clinical disorders has been explored – for example, eating disorders [18]; depression [19]; and anxiety disorders [20]. However there is relatively little research about perfectionism and CFS: one study [21] found that CFS patients self-report as having high standards, while several others [22–24] found a link between CFS and negative aspects of perfectionism (doubts about actions, concern over mistakes). More specifically, 'self-critical' perfectionism has been shown to be related to increased stress sensitivity and depression in CFS patients [25].

The relationship between perfectionism and acceptance in CFS has hitherto not been explored. It is possible that participants with higher levels of perfectionism are more intolerant of symptoms and therefore less likely to be accepting of them. We hypothesise that lack of acceptance will be correlated with perfectionism, and aspects of perfectionism related to personal standards will improve after CBT as CBT addresses unhelpful perfectionistic beliefs if necessary.

Aims and hypotheses

This study aimed to extend the research of Van Damme et al. [13], exploring the relationship between acceptance and wellbeing using a larger cohort, and then considering the relationship between acceptance and aspects of perfectionism, and their relative contribution to fatigue and functioning in people with CFS. A further aim of this paper was to examine whether acceptance and perfectionism improved over time in CFS patients who received CBT, by comparing baseline, discharge and 3-month follow-up questionnaires.

We hypothesised that 1) increased acceptance would be related to improved fatigue and improved psychological wellbeing; 2) there would be a significant relationship between lack of acceptance and perfectionism and that they would be associated with fatigue and disability; 3) that acceptance and aspects of perfectionism related to the individual such as concern over mistakes and doubts about actions would improve after a course of CBT.

Method

Participants

Participants were patients referred by their GP or hospital consultant to a specialist CFS Research and Treatment Unit in London to assess whether they fulfilled the CFS diagnostic criteria. A thorough assessment was completed and routine investigations as recommended by the

NICE guidelines [26] ensured that other causes for fatigue were excluded. A total of 283 patients were assessed.

Treatment

Eleven trained cognitive behavioural psychotherapists, nurses, or clinical psychologists delivered CBT to patients. All were experienced in the treatment of CFS and had been qualified for a mean of 10.6 years (S.D. 6.35, range 4–21). All had supervision with someone experienced in CFS and CBT. Patients typically received one session per fortnight, and each patient received approximately 12 sessions of CBT.

Outcome measures

Fatigue

The Chalder Fatigue Scale [27] was used to measure the severity of physical and mental fatigue. This is a brief scale which asks patients to rate their fatigue symptoms on a Likert scoring system (0–33), with high scores indicating high levels of fatigue. This scale has been shown to be reliable and valid [28].

Physical functioning

Patients were given 10 items from the Short Form Health Survey, or SF-36 [29], where they were asked to rate how much their health limits them in certain activities (e.g. strenuous sports, carrying groceries, and climbing stairs) ranging from "limited a lot" to "not limited at all". Higher scores indicate better health. This measure has shown good reliability and validity [30,31].

Work and social adjustment

The Work and Social Adjustment Scale [32] is a 5-item measure of impairment in day-to-day functioning. Patients responded to the questions about different aspects of impairment by selecting a number between 0 ('not at all') and 8 ('severely impaired'). Higher scores indicate a higher level of impairment. This measure has been shown to have excellent reliability [33].

Process measures

(Lack of) Acceptance

The study used a slightly adapted version of the Chronic Pain Acceptance Questionnaire or CPAQ [34]. The original questionnaire is divided into two factors – activity engagement and pain willingness. For the purposes of this study, only the pain willingness subscale was used, and the word 'pain' was replaced with 'fatigue'. The concept of willingness refers to the recognition that avoidance and control of pain are often not viable. So, fatigue willingness refers to feeling little need to attempt to avoid or control fatigue. Nine items, including statements such as "Keeping my fatigue level under control takes first priority whenever I'm doing something" and "I need to concentrate on getting rid of my fatigue" are scored on a 7-point Likert scale (where 0='never true' and 6='always true') so the higher the score, the higher the lack of acceptance. Cronbach's alpha was high in this study (.83).

Perfectionism

Four subscales from the Frost Multidimensional Perfectionism Questionnaire [35] were given to patients to assess different aspects of perfectionism: concern over mistakes, doubts about actions, parental expectations, and parental criticism. These subscales were chosen because previous studies have suggested that these represent 'negative evaluation concerns' [36] or a 'negative' form of perfectionism. The reliability and validity of this questionnaire have been demonstrated [37].

Depression

Patients were asked to fill out the depression subscale of the Hospital Anxiety and Depression Scale [38], with 7 questions designed

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