

Well-being in patients with chronic fatigue syndrome: The role of acceptance

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Abstract

Objective: Research in chronic pain patients has shown that accepting the chronic nature of their illness is positively related to quality of life. The aim of this study was to investigate whether acceptance is also associated with better well-being in patients suffering from chronic fatigue syndrome (CFS). **Methods:** Ninety-seven patients completed a battery of questionnaires measuring fatigue, functional impairment, psychological distress, and acceptance. **Results:** Results indicated that acceptance has a

positive effect upon fatigue and psychological aspects of well-being. More specifically, acceptance was related to more emotional stability and less psychological distress, beyond the effects of demographic variables, and fatigue severity. **Conclusion:** We suggest that promoting acceptance in patients with CFS may often be more beneficial than trying to control largely uncontrollable symptoms.

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Introduction

Chronic fatigue syndrome (CFS) is a severe and invalidating experience of fatigue, which lasts for at least 6 months [1]. Most patients report a low ability in somatic, psychological, cognitive, and social functioning, which often leads to professional difficulties [2–6]. As yet, the experience of chronic fatigue is medically unexplained [7]. In an attempt to diminish suffering and improve quality of life, several models have been developed, addressing possible initiating, exacerbating, and maintaining factors [8,9]. One factor that has proven to be related to the functioning of CFS patients is self-efficacy. Research has

revealed that self-efficacy, defined as the perceived ability to control illness, has a positive effect on fatigue and associated impairments [10–12]. Although there is definitely merit in the idea that active attempts to control fatigue and disability contribute to a better quality of life, there may sometimes be negative effects. In particular, research in patients with chronic pain has pointed out that attempts to control uncontrollable pain may prove futile and may only fuel frustration, distress, and hypervigilance to symptoms [13–15]. Research with chronic pain patients has shown that giving up attempts to control pain and accepting chronic pain lead to a better adjustment to chronic pain [16]. In a questionnaire study [17] in 160 chronic pain patients, acceptance of pain was associated with less psychological distress, and less disability, even after controlling for the effects of pain severity. Similar results emerged from a study in patients with rheumatoid arthritis and multiple sclerosis [18]. That study further showed that acceptance was associated with an increase in physical and psychological

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health status at a 1-year follow-up. Viane et al. [19] investigated the role of acceptance in well-being in two questionnaire studies with chronic pain patients. Both studies showed that acceptance was related to better psychological but not physical well-being.

Acceptance is a complex construct that consists of several components. Although many patients relate acceptance to giving up, recent studies have explicitly rejected this negative view [20]. McCracken and Eccleston [14] have argued that acceptance is best conceived of as halting the dominant search for a definitive solution of physical complaints and as a reorientation of attention towards positive everyday activities and other aspects of life. Research has further indicated that acceptance often involves a search for a new identity, implying a re-evaluation of personal goals, values, and life priorities [21].

Although the idea of acceptance is less common in the field of CFS than in chronic pain, there is ongoing discussion in clinical practice about whether the aim of cognitive-behavior therapy should be learning to control fatigue or pacing and accepting limitations. In the present study, we investigate whether acceptance contributes to well-being in patients with CFS. We hypothesize that acceptance will be associated with lower levels of fatigue, psychological distress, and functional impairment.

Method

Participants

The sample consisted of 110 patients with CFS who were on a waiting list for cognitive-behavioral treatment in the Ghent university hospital. All patients fulfilled the CDC [1] criteria for CFS. The study was approved by the local ethical committee, and all patients provided informed consent. They received a package of questionnaires by mail and were requested to send it back after completion.

Questionnaires

We used three indicators of well-being: fatigue [Checklist Individual Strength (CIS)], psychological distress [Hospital Anxiety and Depression Scale (HADS)], and functional impairment [Sickness Impact Profile-68 (SIP-68)]. Acceptance was measured by the Illness Cognition Questionnaire (ICQ). These instruments are further discussed below.

We assessed fatigue severity by the self-reported fatigue subscale of CIS [22]. This instrument measures different aspects of fatigue during the past 2 weeks on a 7-point scale: (1) self-reported fatigue (8 items, e.g., “I feel tired”), (2) concentration (5 items, e.g., “I have trouble concentrating”), (3) motivation (4 items, e.g., “I feel no desire to do anything”), and (4) physical activity (3 items, e.g., “I have a low output”). Research has shown that CIS is reliable and valid both in healthy individuals and patients with CFS [12].

We measured psychological distress by the Dutch version of HADS [23], which was developed to measure anxiety and depressive symptoms in patients with somatic disorders. The HADS consists of 14 items divided into two equal subscales: anxiety and depression. The total score is a valid indicator of psychological distress [24]. In order to avoid content overlap with fatigue, we omitted one item from the depression subscale (item 8: “feeling slowed down”).

We used the short version of the SIP [25,26] to assess functional impairment. This questionnaire consists of 68 items and assesses the impact of illness upon various domains of daily functioning. The short version has six subscales: (1) “Somatic autonomy” assesses the level at which basic somatic functions can be performed without help (17 items, e.g., “I stand up only with someone’s help”). (2) “Mobility control” describes the level of control over one’s body (12 items, e.g., “I walk shorter distances or stop to rest often”). (3) “Psychic autonomy and communication” describes the level at which one is able to operate independently in areas of mental functioning and verbal communication (11 items, e.g., “I have difficulty doing activities involving concentration and thinking”). (4) “Social behavior” assesses the consequences of the health problem on one’s functioning in relation to other people, such as sexual activity and visiting friends (12 items, e.g., “I am doing fewer social activities with groups of people”). (5) “Emotional stability” describes the effects of the health problem on one’s emotional status (6 items, e.g., “I often act irritable toward those around me, for example, snap at people, give sharp answers, criticize easily”). (6) “Mobility range” relates to limitations in the range of behaviors due to the health status (10 items, e.g., “I am doing any of the house cleaning that I would usually do”). Higher scores are indicative of more functional impairments. A total score can be computed. Psychometric research has indicated that SIP-68 is reliable and valid [27].

We assessed acceptance by using ICQ [18], which measures illness cognitions in patients with chronic diseases. This instrument is mainly used in patients with rheumatoid arthritis, multiple sclerosis, or chronic pain, but is applicable to other chronic illnesses. The ICQ consists of 18 items, measuring three types of illness cognitions, which reflect different ways of dealing with a chronic disease: (1) helplessness (6 items, e.g., “My illness controls my life”), (2) acceptance (6 items: “I can handle the problems related to my illness,” “I have learned to live with my illness,” “I have learned to accept the limitations imposed by my illness,” “I can accept my illness well,” “I think I can handle the problems related to my illness, even if the illness gets worse,” and “I can cope effectively with my illness”), and (3) perceived benefits (6 items, e.g., “Dealing with my illness has made me a stronger person”). Psychometric research indicates that the ICQ is a reliable and valid instrument [18].

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