

Illness perceptions and mood in chronic fatigue syndrome

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Abstract

Background: Individual beliefs and cognitions may affect adjustment to chronic fatigue syndrome (CFS) and illness perceptions, in particular, have been reported to correlate with both disability and psychological adjustment to CFS in self-diagnosed cases. **Objectives:** The aim of the present study was to examine these relationships in a clinic sample of CFS patients assessed by both a physician and psychiatrist. **Method:** A sample of 173 patients referred to a multidisciplinary CFS clinic and fulfilling current operational criteria for CFS [8,10] were randomly selected from the clinic database and surveyed with the Hospital Anxiety and Depression scale, Fatigue Questionnaire and Illness Perceptions Questionnaire [15–17]. **Results:** A total of 126 patients responded (73% response rate). The illness perception components studied were consequences (of illness), illness identity,

causes (of illness), the ability to control/cure the illness and (expected) timeline of the illness. These components accounted for 15%, 28% and 30% of the variance in levels of fatigue, depression and anxiety, respectively. Two of the illness perception components (consequences and illness identity) were stronger predictors of fatigue score than mood scores. **Conclusions:** These findings confirmed in a clinical sample that illness perceptions are associated with variation in both disability and psychological adjustment in CFS. Illness perceptions may have an important and long-lasting effect on adaptation to CFS, and it is necessary to have a greater understanding of their role in order to tailor effective interventions for the condition. © 2001 Elsevier Science Inc. All rights reserved.

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Introduction

The importance of illness representations and cognitions in adjustment to long term conditions, such as chronic fatigue syndrome (CFS) has been recently recognised [1]. Petrie et al. [2] have found that catastrophic thinking was related to increased disability and fatigue in CFS patients, even controlling for the number of symptoms, psychological disturbance and help-seeking behaviour. Ray et al. [3] found that aspects of illness beliefs could predict progression of CFS with a stronger belief in perceived controllability of the condition at initial assessment being linked to better outcome.

Mood may also have an effect on adjustment in CFS. Ray et al. [4] has found that emotional distress correlates with factors that are predictive of illness severity (i.e., cognitive difficulty). This suggests disturbed mood can indirectly affect CFS by exacerbating symptoms, thus, amplifying the severity of the individual's illness experience [5]. All these findings point to the concept of 'illness perceptions' [6], where individuals create a cognitive model of their illness, which may influence their adjustment to a chronic condition.

This cognitive model is supported in CFS by the study of Moss-Morris et al. [7] who found that illness perceptions were related to levels of disability and psychological adjustment. The generalisability of their findings is limited as the CFS sample that they studied was of self-diagnosed cases obtained through the Australian and New Zealand Myalgic Encephalomyelitis Society (ANZMES) — a national postal-based community service. The use of this sample poses several problems. The study relied on self-identified suf-

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ferers who may not have fulfilled CFS operational criteria [8]. Secondly, a further selection bias is that the ANZMES is a self-help organisation and one follow up study [9] found that members of self-help groups had greater functional impairment than nonmembers. Finally, as discussed by Sharpe et al. [9], patients who believe they have ‘M.E.’ may have different illness characteristics from those who consider themselves to be CFS sufferers — that is, greater disability, but less psychological distress.

For these reasons, it was felt important to reassess the role of illness perception in a less selected clinic sample of CFS patients, comprehensively assessed according to recent CDC criteria [8]. It was aimed to assess which illness perception components had greatest influence on disability (fatigue) and adjustment (mood), and to explore the relative importance of mood and illness perception components on fatigue.

Method

Selection and characteristics of participants

Characteristics of clinic sample

The patients contacted for this study ($n=173$) had attended a CFS clinic in tertiary care. They were chosen randomly from a database of 355 consecutive referrals between June 1995 and February 1997 who all fulfilled both the Oxford criteria for CFS [10] and the 1994 CDC criteria for CFS [8]. All patients had a primary complaint of chronic disabling mental and physical fatigue and were firstly assessed by an infectious diseases physician (PS), then by a liaison psychiatrist (SL). Patients with concurrent psychiatric diagnoses “allowable” under these criteria were included in the study. Psychiatric diagnoses were made according to DSM-IV criteria as described elsewhere [12–14]. By the time, the study started, 80 (46.2%) patients had completed a group treatment programme, which incorporated cognitive behavioural principles and graded activity [11,12] and 50 (28.9%) were on the waiting list for this treatment.

Characteristics of respondents

A total of 126 patients responded (73% response rate) to the survey. Men comprised 37% of the respondents. The average age of the respondents was 43.3 years (95% CI 41.2, 45.4 years), and their mean illness duration was 62.2 months (95% CI 0, 181.2 months)¹. The proportion of patients who initially had psychiatric comorbidity did not significantly differ (χ^2 2.04; df 1; NS) between responders and nonresponders. There were no significant differences in age, illness duration, sex ratio, HAD anxiety score, depres-

sion score or Fatigue Questionnaire score between responders and nonresponders.

Measures used in survey

- Fatigue Questionnaire [15]: This 14-item self-rating scale is a measure severity of mental and physical fatigue. The scale has acceptable internal consistency, face validity and discriminant validity. The cut-off score suggested by the authors was used to define “chronic fatigue cases.”

- Illness Perception Questionnaire [16]: This measures components of illness representation, based on Leventhal et al.’s [6] cognitive model of illness perceptions. It has five scales that assess: ‘Illness Identity,’ ‘Cause,’ ‘Timeline,’ ‘Consequences’ and ‘Control/cure.’

‘Illness Identity’ measures the number and frequency of various symptoms a patient may experience in his/her illness. The remaining four components are measured by Likert scaling. The ‘Cause’ scale consists of 10 items measuring perceptions about possible causes of the illness, and each item is treated as an independent variable. However, Moss-Morris et al. [7] derived an ‘emotional cause’ score in their study by combining scores for the ‘own behaviour,’ ‘state of mind,’ and ‘stress’ items, but the “physical causes” item scores remained independent as they were not strongly intercorrelated. The ‘Timeline’ scale consists of three items measuring patient beliefs about the perceived duration of the illness. ‘Consequences’ contains seven items measuring beliefs about the expected effects/outcomes of the condition. Finally, ‘Cure/Control’ scale has six items measuring perceptions about degree of control the individual feels they have over the illness and whether they believe it to be curable. This questionnaire has been found to have good reliability and validity in different ‘illness’ groups, including CFS [16].

- Hospital Anxiety and Depression Scale [17]: This is a 14-item scale used as a screening and severity measure for anxiety and depression in medical outpatients. The suggested cut-off scores were used.

Sampling procedure and survey method²

Out of 355 possible patients (48.7%) on the CFS database, 173 were selected via computer-generated random number lists, with the randomisation process being stratified by sex. A postal battery including the above questionnaires and a letter explaining the study was sent to each patient between June and October 1997. These were returned in the addressed envelope that was provided and all questionnaires were number coded so that respondents could not be identified. In the case of nonresponse, a reminder was sent.

¹ The lower 95% confidence interval has been changed to zero, otherwise, this value would have been negative.

² Ethical permission had been previously obtained by LRECS in Leeds for related studies of treatment and outcome in CFS.

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