

Illness experience, depression, and anxiety in chronic fatigue syndrome

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Abstract

Objective: Given the high rate of psychiatric comorbidity with chronic fatigue syndrome (CFS), we considered two possible correlates of anxiety and depression: lack of illness legitimization and beliefs about limiting physical activity. **Method:** A total of 105 people diagnosed with CFS reported on their experiences with medical professionals and their beliefs about recovery and completed the depression and anxiety subscales of the Brief Symptom Inventory. **Results:** Those who said that their physician did not legitimize their illness (36%) had higher depression and anxiety scores (P 's < .05) than their counterparts. Those who

believed that limiting their physical exertion was the path to recovery (55%) had lower depression and anxiety scores (P 's < .01) than their counterparts. **Conclusion:** Lack of illness legitimization ranked high as a source of dissatisfaction for CFS patients, and it may aggravate psychiatric morbidity. Many CFS patients believed that staying within what they felt to be their physical limits would improve their condition. This belief, and possibly an accompanying sense of control over their symptoms, may alleviate psychiatric morbidity. © 2002 Elsevier Science Inc. All rights reserved.

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Introduction

Investigations of the rate of comorbidity of depression and anxiety with chronic fatigue syndrome (CFS) suggest that approximately half of CFS patients experience anxiety and depressive disorders [1–3]. Moreover, the physical symptoms of CFS are similar to those of depression [4]. Attendant with these inquiries are discussions of whether depression or anxiety are causes or results of CFS [5–7]. The dispute over the relations between CFS and depression or anxiety notwithstanding, it is important to delineate factors related to increased depression and anxiety in CFS patients.

CFS is characterized by debilitating fatigue that persists for more than 6 months, impairs functioning to less than 50% of premorbid levels, and cannot be attributable to any

other illness—a set of criteria adopted by the Centers for Disease Control [8]. Additional minor criteria may include decreased ability to concentrate, mild fever, sore throat, and tender lymph nodes. Estimates of point prevalence rates suggest that between 0.3% and 2% of the population has CFS [9,10].

Those with CFS experience an illness of unknown etiology and uncertain organic pathology, receive a diagnosis of exclusion, and often undertake treatments of ineffective or undetermined impact. An illness of stealth, CFS continues to evade endeavors to locate a specific biological marker. Faced with such an illness, physicians may be tempted to minimize the reality of the illness, to attribute it to a psychological cause, or simply to avoid diagnosing the patient with what the physician may believe is a potentially harmful label. Yet, these approaches may be perceived negatively by some patients with CFS, prompting feelings of isolation and shame [11,12]. A recent study by Deale and Wessely [13] found that patient dissatisfaction was associated with delay, dispute, or confusion over

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diagnosis, and with diagnoses of a psychiatric nature. For these reasons, we anticipated that those with CFS mentioning a lack of legitimization by their physician would report more depression and anxiety than those not citing such a lack of legitimization. The concept of legitimization of an illness (which has been previously articulated by Ware [12]) indicates that—according to patient perception—the physician formally acknowledges the reality of the patient’s experiences and approaches the illness as though it were any other process in need of medical attention.

The effectiveness of various therapies for CFS is disputed, but there is mounting evidence that cognitive behavioral therapy can improve fatigue and day-to-day functioning, primarily by altering illness beliefs and coping mechanisms, building the patient’s sense of control over their symptoms, and encouraging steady activity [14–16]. The belief that exercise must be avoided has been found to predict poor outcome [14,15,17]. In fact, there is disagreement about the virtues of rest versus exercise in the management of CFS. Whereas the dominant scientific paradigm denounces “rest cure” therapy for CFS, instead advising graded exercise [18–20], an alternative voice claims the necessity of rest, giving credence to patients’ fears of adverse effects from exercise [21]. Those with CFS have been found to disagree with many physicians about the effects of rest, tending to believe that increased rest is the most appropriate form of therapy [22]. Given this, we anticipated that CFS patients who recognized the importance of staying within their physical limitations (which may allow for both rest and activity) would report less depression and anxiety than their counterparts.

Method

Overview

The CFS sample was drawn from two sources: (a) members of the Myalgic Encephalomyelitis Society of British Columbia (MEBC) with CFS and (b) patients of an infectious diseases specialist in Vancouver. Those indicating a willingness to take part in the study in response to an initial letter were phoned to set an interview date, place, and time. Most interviews were scheduled in the respondent’s

Table 1
Dependent measures

“What is the most unhelpful or upsetting thing that a medical professional has said or done to you?” (unhelpful question)
“What is the most helpful thing that a medical professional has said or done to you?” (helpful question)
“There is little agreement among medical professionals regarding how people recover from CFS or whether or not they show improvement. Nevertheless, some people with CFS have one or more hunches or theories. Do you have any hunches or theories about how your own improvement or recovery can be facilitated? If yes, what are they?” (beliefs about recovery question)

Table 2

Frequencies of responses by CFS patients to the question of the most unhelpful or upsetting action by a physician

Content categories of responses	No. of responses	%
A specific course of treatment	42	40.0
Increase activity	23	21.9
Medication	10	9.5
Diet change	4	3.8
Other	4	3.8
Diagnostic procedures	2	1.9
Lack of legitimization via disbelief or nondiagnosis	38	35.5
Psychological diagnosis	30	28.0
Emotionally unsupportive action	29	27.1
Ignorance of CFS	20	18.7
Administrative mismanagement	6	5.6
Nothing was unhelpful	6	5.6
Other	6	5.6

Totals exceed 100% because multiple responses were coded per participant.

home. Respondents were asked for permission to tape-record the interview, which was conducted by one of a team of six trained interviewers. Respondents were also given a questionnaire package to complete at their leisure and return in a self-addressed stamped envelope. Of the 144 eligible people from MEBC, 89 (62%) responded to the letter and were interviewed. No data were collected from those who chose not to participate. An additional 16 people were obtained through the infectious diseases specialist, yielding a total sample of 105.

Dependent measures

The interview was developed to assess key constructs, including interactions with medical professionals and beliefs about recovery (Table 1). It was pilot tested on eight people with CFS to determine length, suitability of questions, and

Table 3

Frequencies of responses by CFS patients to the question of the most helpful action by a physician

Content categories of responses	No. of responses	%
Legitimization of illness via belief or diagnosis	55	52.4
A specific course of treatment	42	40.0
Advice to heed physical limitations	24	22.8
Other	8	7.6
Medication (e.g., antibiotics, antidepressants)	5	4.8
Diet change	5	4.8
Positive attitude advised	5	4.8
Allergy treatment	3	2.9
Diagnostic tests	2	1.9
Emotional support	39	37.1
Knowledge of CFS	6	5.7
Other	7	6.7
Worked with other medical professionals as a team	5	4.8
Nothing was helpful	3	2.9

Totals exceed 100% because multiple responses were coded per participant.

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