

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.

Table 4
t Test analyses to detect an association between psychiatric morbidity and illness experience

Variable	Those lacking illness legitimization (<i>n</i> = 38)	Others (<i>n</i> = 67)	Those heeding physical limits (<i>n</i> = 58)	Others (<i>n</i> = 47)
BSI-Depression score	2.26 (S.D. = 0.98) <i>P</i> = .041	1.90 (S.D. = 0.68)	1.83 (S.D. = 0.67) <i>P</i> = .001	2.40 (S.D. = 0.92)
BSI-Anxiety score	2.31 (S.D. = 0.89) <i>P</i> = .038	1.97 (S.D. = 0.70)	1.88 (S.D. = 0.61) <i>P</i> = .050	2.20 (S.D. = 0.87)

S.D. = standard deviation.

adequacy of the proposed methodology. Respondents also completed the depression and anxiety subscales of the Brief Symptom Inventory [23]. Each item was rated on a five-point scale ranging from 1 = *not at all* to 5 = *extremely*, indicating how much it bothered or distressed the respondent in the past month.

Coding of open-ended questions

Answers to the open-ended questions were transcribed from tape recordings. Codes—categories for responses, grouped according to common themes—were developed by examining a random sample of responses. Two independent raters then coded each response. Discrepancies were resolved by discussion. Cohen's kappa [24] was 0.77 for the unhelpful question, 0.80 for the helpful question, and 0.76 for the beliefs about recovery question.

Results

Respondents were predominantly White (96%), and there was a somewhat higher proportion of females (88%) than would be expected given epidemiological statistics (women develop CFS at a rate of 1.5 times that of men) [25]. Respondents noticed onset of their symptoms a mean of 8 years earlier (range = 1–22 years). The number of years since diagnosis ranged from 1 to 18, with an average of 5 years. Respondents had an average of 15 years of education, a mean age of 47, and a mean personal income (1994) of \$19,000 (Can).

The most frequent response (36%) to the unhelpful question was that, in the respondent's opinion, the physician failed to legitimize or acknowledge the reality of the illness

(as experienced by the patient) (Table 2). Sample responses included: "My physician denied me, and told me that there was nothing wrong," "A cardiologist completely dismissed my counsel, got the story wrong why I came in, and patted me on the back and said 'go home and enjoy your family,' so basically very dismissive," and "My GP withheld the diagnosis thinking it would be good for me." Similarly, 28% of respondents said that one of the most unhelpful things their physician had done was to give them a psychological "diagnosis," such as "it's all in your head" or "My physician told me CFS is a personality disorder, and people can't change their personality." It is noteworthy that when asked about the most helpful thing their physician had said or done, 52% noted some form of legitimization of the disease, either through diagnosis or at least in the belief in the physical presence of symptoms (Table 3). An examination of the answers to the helpful and unhelpful questions suggests that the type of advice considered helpful was often in direct opposition to the type of advice considered unhelpful. For example, recommendations to heed physical limitations were viewed as especially helpful, whereas advice to increase activity was viewed as unhelpful. The 36% of respondents who, in response to the unhelpful question, reported that their physician had failed to legitimize their illness had significantly higher depression and anxiety scores than those providing other responses (Table 4).

Respondents were also asked how they thought their recovery could best be facilitated (Table 5). Fifty-five percent said that adhering to personal physical limitations was the key to their rehabilitation. Those coded for such a response had significantly lower depression and anxiety scores than those providing other responses (Table 4). Sample responses included: "Pace myself, rest, approach it cautiously to ensure I don't get tired" and "Controlling impulses to do cognitive and physical work when not up to it. Controlling myself from doing things that will make days or weeks of illness."

Table 5
 Frequencies of responses to the question of how recovery or improvement could be facilitated

Content categories of responses	No. of responses	(%)
Adherence to personal limit of overexertion	58	55.2
Improved psychological health	48	45.7
Alternative/homeopathic therapies	31	29.5
Healthy and/or specialized diet	28	26.7
Competent allopathic medical care	13	12.4
Nothing	11	10.5
Other	6	3.8
Passage of time	2	1.9

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

Discussion

Patients with CFS who said their physician failed to legitimize their illness reported more psychological distress than their counterparts. Lack of specific and practical diagnostic measures for this disease may leave both physicians and patients mired in anxious uncertainty, and physicians may prefer to obtain tangible evidence of disease

before discussing an impression with patients. Although such objective detachment is defensible from a diagnostic perspective, those with CFS who have concerns about their health seem not to appreciate responses that fail to legitimize their illness.

The fact that legitimization in the form of mere diagnosis was cited so frequently as the most helpful action rendered by a medical professional may signal the lack of treatment available for this disease (i.e., there is not much that a physician can offer beyond a diagnosis). It also suggests that one of the most important services that physicians offer and that patients seek is the partial sense of control over an illness that a diagnosis affords. Research indicates that some physicians are hesitant to use terms such as “CFS” owing to fear that patients may overidentify with a dismal diagnosis [26]. Another concern is the possibility of actually teaching some patients to be sick by encouraging them to engage in self-protective illness behaviors [27,28]. The present data suggest that many people with CFS have a need for their illness to be formally recognized by their physician, and that diagnosis is a primary tool for this legitimization to occur. Dealing with an “invisible” chronic multisymptom condition may be more difficult without the validation of a medical label. Furthermore, although stigma has often been associated with the label CFS, in many interpersonal contexts, a medical label may serve to deflect blame away from the patient.

Health care professionals can legitimize the illness without necessarily subscribing to a limited mind–body dualism. Many patients will not likely accept the attribution that the illness is purely psychological, and may be more receptive to the idea that a range of psychosocial factors may be implicated in the illness. For example, in the present study, 46% of participants reported that improved psychological health was important in terms of their recovery. Patients also may be willing to accept the notion that chronic illness includes a range of psychosocial consequences such as disruptions in physical, social, recreational, and vocational activities; sleep; mood; relationships; and medication use, to name a few. Once a multidimensional perspective is accepted, patients may be more open to consider making changes in these areas, not to be “cured,” which thus far has been an elusive goal, but to enhance their level of functioning and possibly facilitate their recovery.

Although only 23% of the sample said that the most helpful advice from their physician was to heed their physical limit of exertion, 55% believed their recovery will be facilitated by staying within the bounds of their physical limitations. We found that lower levels of depression and anxiety were associated with this belief. Given this, physicians might do well to encourage patients to gradually increase activities, while paying attention to and heeding their body’s signals. Patients may thereby acquire a sense of predictability of symptoms by recognizing patterns of fatigue associated with physical exertion, while maintaining or improving their fitness level. Avoiding activity may lead to short-term improvement in anxiety and depression symp-

toms, but long-term exacerbation of fatigue. Rather than advising patients about the illness and its treatment, suggestions to moderate physical activity were deemed most helpful. In contrast, instructions to increase activity without considerations of context and without acknowledgement of the potential for fatigue and relapse were considered particularly unhelpful.

Unhelpful actions may be the result of a discrepancy between the intent of the medical professional’s statements and the reception and interpretation by the patient. Clinicians may choose to tread carefully when recommending a specific course of treatment, especially when it involves suggestions of increased activity or medication, given that a substantial percentage of CFS patients report that such directives are unhelpful. Advice to increase activity may communicate, perhaps in an unintended way, that the person with CFS is not doing what is appropriate to manage his or her condition, or is to blame for the lack of progress, both likely to be threatening. It is possible that the respondents’ negative reaction to advice to exercise may be due more to a perception that the physician is not legitimating their illness.

That the majority of the sample came from a patient organization raises generalizability issues about the findings. Moreover, no data are available to characterize the differences between those who declined to participate and those who did. The ethnic homogeneity, too, must be noted; those from other cultural backgrounds may have radically differing expectations of their physician. Furthermore, the inherent subjectivity of patient perceptions makes it difficult to conclude which specific behaviors by the physicians will necessarily negatively impact patients’ psychological well-being.

The present findings have implications for the therapist–patient alliance in many unexplainable chronic illnesses. From a rehabilitation perspective, it is preferable to request that patients make slow but consistent progress, rather than suggesting a more regimented and aggressive approach, given that compliance likely will be better in the former instance. This recommendation echoes the existing standard of care for CFS. After all, the most successful rehabilitation plan is one that is accepted and implemented by the patient.

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