"Abnormal" illness behaviour in chronic fatigue syndrome and multiple sclerosis

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Abstract

Objective—To investigate the presence of abnormal illness behaviour in patients with a diagnosis of chronic fatigue syndrome.

Design—A cross sectional descriptive study using the illness behaviour questionnaire to compare illness behaviour scores and illness behaviour profiles of patients with chronic fatigue syndrome and patients with multiple sclerosis.

Setting—A multidisciplinary fatigue clinic and a teaching hospital neurology outpatient clinic.

Subjects—98 patients satisfying the Oxford criteria for chronic fatigue syndrome and 78 patients with a diagnosis of multiple sclerosis.

Main outcome measure—Responses to the 62 item illness behaviour questionnaire.

Results—90 (92%) patients in the chronic fatigue syndrome group and 70 (90%) in the multiple sclerosis group completed the illness behaviour questionnaire. Both groups had significantly high scores on the general hypochondriasis and disease conviction subscales and significantly low scores on the psychological versus somatic concern subscale, as measured in relation to normative data. There were, however, no significant differences in the subscale scores between the two groups and the two groups had identical illness behaviour profiles.

Conclusion—Scores on the illness behaviour questionnaire cannot be taken as evidence that chronic fatigue syndrome is a variety of abnormal illness behaviour, because the same profile occurs in multiple sclerosis. Neither can they be taken as evidence that chronic fatigue and multiple sclerosis share an aetiology. More needs to be known about the origins of illness beliefs in chronic fatigue syndrome, especially as they are important in determining outcome.

Introduction

Despite extensive research over recent years the aetiology and associations of chronic fatigue syndrome remain poorly defined, and "even its nosological existence is subject to dispute."¹ Suggested causes include specific viral infections, immunological dysfunction, and wholly psychological mechanisms.^{2,3} Those who see chronic fatigue syndrome as primarily a psychiatric disorder regard it as a variety of somatisation—that is, "the expression of personal and social distress in an idiom of bodily complaints and medical help-seeking."⁴ In support of this suggestion, two studies found that about 15% of patients with chronic fatigue satisfy American Psychiatric Association criteria⁵ for a diagnosis of somatisation disorder (a severe, chronic form of somatisation),^{6,7} while a further study found that fatigue is reported by 76% of patients who meet the criteria for somatisation disorder.⁸

The concept of somatisation overlaps with that of

"abnormal illness behaviour," which was developed by Pilowsky⁹—drawing on Mechanic's concept of illness behaviour¹⁰ and Parsons's concept of the "sick role."¹¹ Abnormal illness behaviour is—like somatisation—a broad concept; it includes abnormal bodily perception, inaccurate evaluation of health state, and inappropriate action (or inaction) in relation to these perceptions and evaluations. There is an explicit judgment to be made in concluding that a patient is exhibiting abnormal illness behaviour; it is that the doctor does not believe that the patient's objective pathology entitles him to be placed in the type of sick role he expects, for the reasons for which he claims it.⁹

If chronic fatigue syndrome is a variety of somatisation, then we should expect to find evidence of abnormal illness behaviour in patients with the syndrome. Two papers have been published on this topic; both used Pilowsky's illness behaviour questionnaire as a measure of abnormal illness behaviour.¹² Hickie *et al* compared illness behaviour questionnaire scores in 48 patients with chronic fatigue syndrome with those in a general practice sample and patients with somatisation disorder.¹³ They found that patients with chronic fatigue syndrome had high scores for disease conviction and denial and low scores for psychological versus somatic concern. They interpreted this as indicating that the patients had a strong conviction of physical illness and were reluctant to accept a psychological explanation and that they viewed the illness as the sole problem in their lives. Schweitzer *et al* replicated these findings in a study comparing data from 40 chronic fatigue syndrome patients with data from two of Pilowsky's normative samples.¹⁴ In addition, they found that chronic fatigue syndrome patients had high general hypochondriasis scores.

The presence of these illness beliefs is important not only in providing evidence about aetiology. A study of long term outcome in chronic fatigue syndrome suggested that two important factors in predicting a poor outcome are the assignment of a primary psychiatric diagnosis at follow up and the strength of the belief that a physical disease process explained all symptoms.¹⁵ The authors commented that "subjects who deal with distress by somatisation...and who discount the possible modulating role of psychosocial factors are more likely to have an unfavourable outcome."¹⁵

We wanted to confirm whether patients with chronic fatigue syndrome have abnormally high levels of disease conviction and if so whether it is associated with other elements of abnormal illness behaviour or is, instead, merely a corollary of chronic illness. We studied illness behaviour in chronic fatigue syndrome and compared the results with those from a group of patients with a chronic illness in which the presence of organic pathology is not in doubt. We chose multiple sclerosis because it is associated with fatigue¹⁶ which seems independent of the neurological deficits and

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does not correlate well with depression.¹⁷ It is also similar to chronic fatigue syndrome in tending towards a relapsing and remitting, uncertain course and often being characterised by rather non-specific symptoms.

Apart from a study comparing chronic postviral fatigue with neuromuscular and affective disorders,⁷ we are not aware of any studies comparing chronic fatigue syndrome patients with patients suffering another chronic condition.

Subjects and methods

Patients with chronic fatigue syndrome were interviewed at a multidisciplinary fatigue clinic at Seacroft Hospital, which was set up by a consultant in infectious diseases (PS) in collaboration with a consultant in liaison psychiatry (AH).¹⁸ Each new patient was initially seen by the consultant in infectious diseases or his senior registrar for a thorough medical history, physical examination, and investigations to exclude any detectable organic cause for the symptoms. If no such cause was evident the patient was assessed in the psychiatric limb of the clinic. Psychiatric assessment included history, mental state examination, and cognitive state examination. Of the first 100 patients attending the clinic who were referred to the psychiatric limb (and from whom the 98 patients in this study were drawn), only one refused to see the psychiatrist. Consecutive attenders who met the Oxford criteria for a diagnosis of the chronic fatigue syndrome¹⁹ (see box) were asked to take part in the study. Sampling and data collection took place in April 1991–October 1993.

Patients with multiple sclerosis were seen in the multiple sclerosis outpatient clinic of St James's University Hospital. All patients are diagnosed by the consultant neurologist in charge (MJ). Consecutive attenders between March 1992 and October 1993 were asked to take part. There was an overlap of 20 months in the collection of data from the chronic fatigue and multiple sclerosis patients, which represented the entire period of collection from the multiple sclerosis group.

Both groups of patients completed Pilowsky's illness behaviour questionnaire at presentation. The questionnaire covers hypochondriacal responses, denial, and changes in affect and assesses the extent to which such psychological states may explain apparently exaggerated responses to illness.¹² It consists of 62 items, from which the following seven subscale scores are derived.

General hypochondriasis (GH) refers to anxious concern about one's state of health.

Disease conviction (DC) refers to affirmation that physical disease exists, symptom preoccupation, and rejection of the doctor's reassurance.

Psychological versus somatic concern (P/S)—This factor is bipolar and refers to the attribution of illness to either psychological or physical causes. A low score indicates a tendency to somatise concerns.¹²

Affective inhibition (AI) refers to difficulties in expressing feelings—especially negative feelings—to others.

Affective disturbance (AD) refers to feelings of anxiety or sadness, or both.

Denial (D) refers to a tendency to deny any life stresses and attribute all problems to the effects of one's illness.

Irritability (I) refers to angry feelings or interpersonal friction.

Factor analysis of scores on the seven subscales was carried out by Pilowsky and Spence and generated two second order factors.¹² These group the affective subscales and the disease affirmation subscales and are known as *affective state* (AS) and *disease affirmation* (DA) respectively. They are believed to provide more global aspects of abnormal illness behaviour and can be

Oxford criteria for diagnosis of chronic fatigue syndrome¹⁹

- (1) A syndrome characterised by *fatigue as the principal symptom*
- (2) A syndrome of *definite onset* that is not life long
- (3) The fatigue is *severe, disabling, and affects physical and mental functioning*
- (4) The symptom of fatigue should have been present for a *minimum of six months*, during which it was present for *more than half the time*
- (5) Other symptoms may be present, particularly myalgia and mood and sleep disturbance
- (6) *Certain patients should be excluded from the definition. They include:*
 - (a) Patients with established medical conditions known to produce chronic fatigue (for example, severe anaemia). Such patients should be excluded whether the medical condition is diagnosed at presentation or only subsequently. All patients should have a history taken and physical examination by a competent physician
 - (b) Patients with a current diagnosis of schizophrenia, manic depressive illness, substance abuse, eating disorder, or proved organic brain disease. Other psychiatric disorders (including depressive illness, anxiety disorders, and the hyperventilation syndrome) are not necessarily reasons for exclusion

Italics are ours

calculated by the following formulas. The value for affective state is determined by simple addition of the scores for the contributing subscales, so that $AS = GH \text{ score} + AD \text{ score} + I \text{ score}$. The value for disease affirmation is obtained by adding the disease conviction subscale to the psychological versus somatic concern subscale, the latter being scored in favour of somatic concern, resulting in the equation $DA = DC \text{ score} + (5 - P/S \text{ score})$ respectively, as the maximum possible score for the psychological versus somatic concern subscale is 5. The graphical plot of the illness behaviour profile is produced by using the percentage of the maximum possible score for each subscale or second order factor on the vertical axis (see figure).

We used SPSS for Windows for statistical analysis. Multivariate analysis with Hotelling's T was carried out to test for differences between the two groups of patients, and the illness behaviour profiles were plotted graphically.

Results

Of the patients who were asked to complete the questionnaire, 90 of 98 (92%) with chronic fatigue syndrome and 70 of 78 (90%) with multiple sclerosis completed all 62 questions.

The chronic fatigue syndrome patients comprised 20 men and 70 women with a mean age of 39.5 years (range 19–68). The multiple sclerosis patients comprised 18 men and 52 women with a mean age of 46.0 years (range 27–71). Multivariate analysis showed that age and sex did not influence scores on the illness behaviour questionnaire, so the small differences in demographic detail between the groups did not affect the results.

Details of diagnostic classification according to the Poser criteria²⁰ were available for 65 of the 70 multiple sclerosis patients. The case notes of one patient were untraceable. In the remaining four cases the participating neurologist (MJ) was satisfied that a diagnosis of multiple sclerosis had been established, though the patients had been diagnosed and had any investigations done before they moved into the area. The original information was not available for these patients and we could not therefore classify them according to the

Illness behaviour profiles in chronic fatigue syndrome (— (n=90)) and multiple sclerosis (--- (n=70)) and, for comparison, normative data used in development of illness behaviour questionnaire (—). By convention, values for each subscale and second order factor are plotted on vertical axis as percentage of maximum possible scores

Poser criteria. Of the 65 cases which were classified, 37 (57%) were category A (clinically definite), 10 (15%) category B (laboratory supported definite), 17 (26%) category C (clinically probable), and one category D (laboratory supported probable). The course of the condition was known for 69 of the 70 patients, the case notes of one patient being untraceable. The course was primary progressive in 12 (17%) cases, secondary progressive in 35 (51%), relapsing and remitting in 16 (23%), and benign in 6 (9%). Though there is a degree of variation between reported figures, these proportions are similar to those in several widely cited studies.²¹⁻²³

It is difficult to define the time of onset in either condition, particularly because of the gradual emergence of symptoms. Time of onset was therefore taken as the time of occurrence of the first symptoms as recalled by the patients and their families. Mean duration of illness at the time of completing the questionnaire was 3.3 (0.5-16.0) years in the chronic fatigue syndrome group and 12.2 (0.5-29.0) years in the multiple sclerosis group.

There were no significant differences between the groups on any of the subscales of the illness behaviour questionnaire. The table shows subscale and second order factor scores for the two groups. Multivariate analysis with Hotelling's T gave an exact F of 2.16 (df=7,152) and significance of F 0.040. However, univariate analysis of scores on the seven subscales showed no significant differences. Values for significance of F were 0.596 for general hypochondriasis, 0.122 for disease conviction, 0.061 for psychological versus somatic concern, 0.502 for affective inhibition, 0.106 for affective disturbance, 0.117 for denial, and 0.063 for irritability. None of the differences between the chronic fatigue syndrome and multiple sclerosis groups were significant at the 0.05 level. Hence the resulting illness behaviour profiles of the two groups are virtually identical.

Illness behaviour questionnaire subscale and second order factor means (SD in parentheses) in chronic fatigue syndrome and multiple sclerosis groups

	Chronic fatigue syndrome (n=90)	Multiple sclerosis (n=70)	Difference between means (95% confidence interval)
General hypochondriasis	2.48 (1.99)	2.31 (1.85)	-0.17 (-0.766 to 0.439)
Disease conviction	4.27 (1.43)	3.91 (1.41)	-0.36 (-0.799 to 0.095)
Psychological versus somatic concern	0.70 (0.80)	0.96 (0.92)	0.26 (-0.018 to 0.532)
Affective inhibition	1.91 (1.75)	2.10 (1.77)	0.19 (-0.366 to 0.744)
Affective disturbance	2.63 (1.73)	2.21 (1.46)	-0.42 (-0.918 to 0.079)
Denial	3.14 (1.62)	3.53 (1.40)	0.39 (-0.088 to 0.856)
Irritability	2.54 (1.81)	2.00 (1.85)	-0.54 (-1.121 to 0.032)
Second order factors:			
Affective state	7.65	6.52	
Disease affirmation	8.57	7.95	

During development of the illness behaviour questionnaire normative data for subscale scores were obtained by Pilowsky and Spence in a general practice population.¹² In relation to these data both the chronic fatigue syndrome and multiple sclerosis groups had illness behaviour scores and profiles which were abnormal. That is, they had high scores on the general hypochondriasis and disease conviction subscales and low scores on the psychological versus somatic concern subscale. These results are illustrated in the figure, which shows the normative data profile for comparison.

Discussion

Our results confirm that patients with chronic fatigue syndrome have high levels of disease conviction and general hypochondriasis and low levels of psychological versus somatic concern. However, we also found that patients with multiple sclerosis have these same abnormalities—with a virtually identical illness behaviour profile. It is therefore wrong to infer that chronic fatigue syndrome is a manifestation of abnormal illness behaviour simply because patients have raised scores on the illness behaviour questionnaire. Zonderman *et al* voiced concern about the validity of the illness behaviour questionnaire, doubting whether it can differentiate appropriate responses to chronic pain and illness from inappropriate responses or abnormal illness behaviour.²⁴

On the other hand, the similarity of illness behaviour profiles in chronic fatigue syndrome and multiple sclerosis cannot be taken as implying that chronic fatigue syndrome does not represent a form of abnormal illness behaviour. Though the final profile of illness behaviours and attitudes was similar in the two conditions, the chronic fatigue and multiple sclerosis patients may have reached their conclusions for quite different reasons.

Patients with chronic fatigue syndrome feel physically ill and their level of functioning is impaired. Despite this they are likely to have been told by doctors and others that they have no identifiable pathology. In the hope of convincing people of the validity of their plight it is unsurprising that they become forceful in their declaration of having a "real disease" (disease conviction); are disinclined to accept a psychological explanation, with the perceived stigma this would entail (somatic versus psychological concern); and become preoccupied by their physical symptoms (general hypochondriasis). In contrast, multiple sclerosis patients gain their understanding of the situation largely in collaboration with doctors. They too report a strong conviction of having a physical disease because they have been told they have one, they have no reason to consider a psychological explanation for their symptoms, and they report worrying about physical symptoms because multiple sclerosis is a notoriously relapsing and disabling disorder.

It is also possible that the apparent close similarity in illness behaviour and attitudes in the two groups was a result of features which the two conditions have in common. There were clear differences between the groups from the point of view of duration of illness, or at least duration since first symptoms, but in some other respects they were similar. Both illnesses are characterised by rather non-specific symptoms, unexplained fatigue, and uncertainty about long term outcome. It may therefore be that uncertainty about the meaning of symptoms or their prognosis accounts for the similarity in the views of patients with chronic fatigue syndrome and multiple sclerosis.

We draw two conclusions from our study. Firstly, the illness behaviour questionnaire seems to be unsatisfactory as a measure of abnormal illness behaviour in chronic fatigue syndrome. If we are to understand

Key messages

- The aetiology of chronic fatigue syndrome is poorly understood
- It is viewed by some as a variety of somatisation or abnormal illness behaviour
- The illness behaviour profile in the chronic fatigue syndrome is the same as that in multiple sclerosis
- Scores on the illness behaviour questionnaire cannot be taken as evidence that the chronic fatigue syndrome is a variety of somatisation
- We need to know more about the origins of illness beliefs in the chronic fatigue syndrome, especially as they are important in determining outcome.

how patients represent illness to themselves and others we need to know not just what beliefs and behaviours the patients have but how they have acquired them and what evidence they use to support them. To our knowledge, a standardised measure for these aspects of the so called illness representation²⁵ does not exist; it needs to be developed.

Secondly, we have confirmed that disease conviction is common in chronic fatigue syndrome. We need to understand not just why that is but whether disease conviction has the relation to outcome reported elsewhere and how such a relation is mediated if it is confirmed.

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Stroke patients' views on their admission to hospital

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Abstract

Objective—To explore which components of care were valued by patients admitted to hospital following a stroke.

Design—Qualitative study using in depth interviews 10 months after the stroke.

Setting—Two adjacent districts in North Thames Regional Health Authority.

Subjects—82 survivors of stroke taken consecutively from a stroke register, 40 of whom agreed to be interviewed.

Results—Patients reported that during the acute stage of the stroke they wanted to put their faith in experienced and trusted experts who would help them make sense of the event, take all the actions necessary to ensure survival, and provide comfort and human warmth during the crisis. In addition to being reassured by the clinical tests and practical nursing help they received, patients valued feeling cared about by the staff. In most cases patients reported that their needs were met; however, the institutional nature of the hospital sometimes obstructed the fulfilment of their needs.

Conclusion—Patients have important psychosocial needs during the acute stage of the stroke,

which are often met by hospital admission. Patients gained benefits from their admission over and above those measurable in terms of morbidity or function. They used a combination of criteria to evaluate their care, focusing on the process as well as the outcome of care. Researchers and clinicians should do likewise.

Introduction

Whether people should be admitted to hospital or cared for at home in the immediate aftermath of stroke has been debated for almost two decades.¹⁻⁶ At first the prevailing belief was that unless it was absolutely necessary, people should be admitted to hospital on medical grounds only, while domiciliary care should be improved so that more patients could remain at home. The arguments in favour of hospital admission focused firmly on the potential clinical benefits, with mortality and levels of disability being the outcomes of interest. Isacs was alone in considering the possibility that less tangible benefits might be gained from hospital admission.⁷ While it is increasingly recognised that patients have psychosocial needs in the aftermath of stroke, it has recently been argued that these needs may be

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