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Patients' perceptions of medical care in chronic fatigue syndrome

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Abstract

This study investigated perceptions of medical care among patients with chronic fatigue syndrome (CFS) referred to a specialist clinic. Sixty-eight patients completed a questionnaire survey on their overall satisfaction with medical care received since the onset of their illness, and their views on specific aspects of care. Two-thirds of patients were dissatisfied with the quality of medical care received. Dissatisfied patients were significantly more likely to describe delay, dispute or confusion over diagnosis; to have received and rejected a psychiatric diagnosis; to perceive doctors as dismissive, skeptical or not knowledgeable about CFS and to feel that the advice given was inadequate or conflicting. Satisfied patients were significantly more likely to perceive doctors as caring, supportive and interested in their illness; to state that they did not expect their doctors to cure CFS and to perceive their GP or hospital doctor as the source of greatest help during their illness. Many patients were critical of the paucity of treatment, but this was not associated with overall satisfaction. The findings suggest that medical care was evaluated less on the ability of doctors to treat CFS, and more on their interpersonal and informational skills. Dissatisfaction with these factors is likely to impede the development of a therapeutic doctor–patient alliance, which is central to the effective management of CFS. The findings suggest a need for better communication and better education of doctors in the diagnosis and management of CFS. © 2001 Elsevier Science Ltd. All rights reserved.

Keywords: Chronic fatigue syndrome; Patient satisfaction; Doctor–patient relationship; UK

Introduction

Chronic fatigue syndrome (CFS) is characterised by medically unexplained, disabling physical and mental fatigue that can persist for many years (Sharpe et al., 1991). It is a poorly understood condition, of uncertain aetiology and little in the way of established treatment. In such circumstances, the quality of the doctor–patient relationship is central: problems in the relationship may contribute to persistent disability, whereas a therapeutic alliance is recommended as a pre-requisite for effective management (Royal Colleges of Physicians, Psychia-

trists and General Practitioners, 1996). Unfortunately, such an alliance can be difficult to establish: many doctors are dissatisfied with or uncertain about the care they provide; they often find consultations difficult, and some see CFS as a “heartsink” condition (Broom & Woodward, 1996; Fitzgibbon, Murphy, O’Shea, & Kelleher, 1997; Ridsdale, Evans, & Jerrett, 1994; Woodward, Broome, & Legge, 1995).

For some CFS patients, consultations with doctors can be equally problematic. In the UK, two small qualitative studies found that many members of CFS patient associations were unhappy with the support and information offered by doctors, and that miscommunication, dismissal and disbelief were widely reported, particularly by women (Ax, Gregg, & Jones, 1997; Cooper, 1997). An American survey of a CFS patient

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association found that members were significantly more dissatisfied with medical care and more litigious than general medical patients (Twemlow, Bradshaw, Coyne, & Lerman, 1997). In Australia, a qualitative study of 50 patients who managed their illness outside the medical system found that two-thirds had experienced difficulties or dispute over the process of diagnosis, with women more likely than men to report unhelpful or distressing consultations (Broom & Woodward, 1996; Woodward et al., 1995).

These studies focused on patients recruited from non-medical settings: the views expressed may not be representative of CFS patients seeking medical care, and there may have been a selection bias towards those who were already dissatisfied (Cooper, 1997). Also, the diagnosis of CFS was only established objectively in the Australian study. It is possible that some of the patients in the UK and American studies had alternative medical or psychological disorders, which may have shaped their experiences of medical care.

In general, CFS patients tend to be high users of medical care, and often consume excessive amounts of time in consultations (Ho-Yen & McNamara, 1996; Lloyd & Pender, 1992). It would be helpful to know how CFS patients recruited from within the medical system feel about the care they receive. This may help doctors to identify and modify sources of tension, and help to build a therapeutic alliance. The purpose of the present study was to examine perceptions of CFS patients seeking medical care, in order to discover how such care is evaluated and to identify specific aspects of medical care associated with satisfaction or dissatisfaction. Since there is some evidence to suggest that men and women with CFS perceive medical care differently, gender differences were also examined.

Methods

Patients were recruited from consecutive referrals to a hospital fatigue clinic over a 12-month period. Patients were eligible for this study if they fulfilled the United Kingdom (UK) criteria for CFS: a main complaint of disabling physical and mental fatigue, present for at least 50% of the time for 6 months or more and unexplained by current medical or psychiatric disorder (Sharpe et al., 1991). Patients were excluded only if they did not meet these criteria.

An experienced doctor who specialised in CFS assessed all patients for eligibility. The diagnosis was made on the basis of the clinical history, mental state examination, physical examination and investigations. All eligible patients were invited to participate in the present study. Informed consent was obtained, and patients who agreed were given a questionnaire to

complete at home and return by post. All were assured that confidentiality would be protected.

The questionnaire (devised by the authors) asked patients for some demographic details and general background information concerning illness duration, causal attributions, doctors consulted and any investigations or treatment. Next, they were asked for their views on five specific aspects of medical care suggested by the existing qualitative studies of CFS patients' views. These were the processes of diagnosis; specialist referrals and investigations; the quality of advice and treatment provided by doctors; doctors attitudes; and sources of help during their illness. Open questions ("what are your views on...") were used to encourage patients to evaluate various aspects of care without being restricted to pre-determined categories. Satisfaction was measured using a single closed question ("overall, are you satisfied with the quality of medical care you have received for CFS?") with a dichotomous yes/no response option. This was intended to provide a simple summary satisfaction rating. There is a risk that dichotomous questions can lead to under-reporting of satisfaction, but this is less likely if (as in the present study) patients are asked to consider specific aspects of medical care first (Bowling, 1997). Throughout the questionnaire, space was provided for additional observations, and an extra page was provided at the end for further comments.

Descriptive statistics were used to examine patient characteristics and responses. Answers to open questions were collated and grouped into categories so that associations could be tested between responses to open questions and overall satisfaction ratings. Differences in categorical variables were tested using the chi square test or Fisher's exact test, and differences in continuous variables were tested using the Mann Whitney U test.

Results

Recruitment

A total of 176 patients were assessed at the fatigue clinic during the period of study. Of these, 85 patients met UK criteria for CFS and were therefore eligible for inclusion. The remaining 91 patients were excluded from the study because they did not meet CFS criteria (fatigue was either insufficiently severe or disabling or it was caused by a current medical or psychiatric condition).

Of the 85 eligible patients, 7 (8%) refused to take part (largely because they were too tired to complete the questionnaire). Ten (12%) agreed, but failed to return their questionnaires. Sixty-eight patients (80%) agreed to participate and returned completed questionnaires. There were no significant differences in referral source, age, gender, illness duration or psychiatric morbidity

between patients who completed questionnaires and those who refused.

Patients' characteristics

Of the 68 patients who took part in the study, 45 (66%) were referred by a general practitioner (GP) and 23 (34%) by a hospital doctor. The mean age of patients was 38.3 years (SD 9.8); 43 (63%) were female, and 45 (66%) were in social classes I or II denoting professional or semi-professional occupations (Classification of Occupations, 1970). The mean illness duration was 4.2 years (SD 4.9). Twenty-three (34%) patients had a comorbid psychiatric disorder (most commonly depression). The patients all attributed their illness to a physical cause (alone or combined with stress) and 17 (25%) were members of a patient association.

All patients had already been diagnosed with CFS either by a GP ($n = 44$, 65%) or a hospital doctor ($n = 24$, 35%). Fifty-nine patients (87%) had been referred to at

least one specialist for investigation of their fatigue (most commonly a neurologist or general physician). Sixty-four patients (94%) reported receiving diagnostic tests (usually blood and urine tests, but also scans, X-rays and muscle biopsies). Fifty-six patients (82%) had been prescribed medication for their symptoms (most commonly antidepressants). Eight (12%) had been referred to counselling and two (3%) to physiotherapy.

There were no significant differences between men and women on any of these variables.

Overall satisfaction with medical care

Forty-two patients (62%) were dissatisfied with the quality of medical care received during their illness and 26 (38%) were satisfied. Twenty-nine (67%) of the women and 13 (52%) of the men expressed dissatisfaction, while 14 (33%) of the women and 12 (48%) of the men were satisfied. These differences were not significant (Fisher's exact test 0.301).

Table 1
Patients' evaluations of aspects of medical care, and association with overall satisfaction ratings

	Dissatisfied patients ($n = 42$)	Satisfied patients ($n = 24$)	Total ($n = 68$)	Difference between groups (p value for Fisher's exact test)
<i>Perceptions of the diagnostic process</i>				
Long delay between onset of symptoms and diagnosis	16 (38%)	3 (13%)	19 (28%)	0.05
The diagnosis was not explained	31 (74%)	10 (42%)	41 (60%)	0.01
A misleading physical diagnosis for symptoms was given	19 (45%)	9 (38%)	28 (41%)	0.29
An unacceptable psychiatric diagnosis for symptoms was given	23 (55%)	6 (25%)	29 (43%)	0.01
At least one doctor stated that the symptoms were definitely not CFS	21 (50%)	6 (25%)	27 (40%)	0.05
<i>Perceptions of specialist referrals & investigations</i>				
Doctors seem reluctant/have to be pressurised to arrange tests/referrals	30 (71%)	9 (38%)	39 (57%)	0.01
Symptoms have not been adequately investigated	14 (33%)	1 (4%)	15 (22%)	0.01
Results of test were not explained	21 (50%)	6 (25%)	27 (40%)	0.05
<i>Perceptions of doctors' attitudes</i>				
Dismissive/ uninterested	16 (38%)	0 (0%)	16 (24%)	0.001
Sceptical or openly disbelieving	27 (64%)	7 (29%)	34 (50%)	0.01
Caring/supportive/interested in the illness	13 (31%)	15 (63%)	28 (41%)	0.05
<i>Perceptions of doctors' advice & treatment</i>				
Doctors consulted do not know about CFS	41 (98%)	13 (54%)	54 (79%)	0.001
Doctors consulted have not given enough guidance on managing illness	39 (93%)	16 (67%)	55 (81%)	0.01
Doctors have given conflicting advice	20 (48%)	5 (21%)	25 (37%)	0.05
Too little treatment is available	20 (48%)	7 (29%)	27 (40%)	0.13
Doctors cannot be expected to cure CFS	1 (2%)	6 (25%)	7 (10%)	0.01
<i>Who has been the greatest source of help during the illness?</i>				
GP or hospital doctor	12 (29%)	17 (71%)	29 (43%)	0.01

Patients' views on aspects of medical care

Patients' responses to the open questions on each of the five aspects of medical care were grouped into the categories shown in Table 1. Associations between the various response categories and patients' overall satisfaction with medical care were tested using Fisher's exact test. There were no significant differences between men and women on any of the response categories.

Discussion

The study found that two-thirds of CFS patients referred to a hospital fatigue clinic were dissatisfied with the quality of medical care received during their illness. Dissatisfied patients were more likely to describe delay, dispute or confusion over diagnosis; to have received an unacceptable psychiatric diagnosis for symptoms; to perceive doctors as dismissive, skeptical or lacking in knowledge about CFS; and to feel that the advice given was inadequate or conflicting. In contrast, satisfied patients were more likely to perceive doctors as caring, supportive and interested in their illness; to state that they did not expect their doctors to cure CFS and to identify their GP or hospital doctor as the source of greatest help during their illness.

This is the first study to examine the views of CFS patients in specialist settings. The diagnosis of CFS was clearly established according to recognised diagnostic criteria and the response rate was good, with no significant differences between those who refused to participate and those who agreed. The characteristics of patients in the present study were similar to those of CFS patients seen in other hospital settings (Sharpe, Hawton, Seagroatt, & Pasvol, 1992; Vercoulen et al. 1996). This suggests that their views may be representative of CFS patients in specialist settings generally, at least in the UK. However, the findings should be interpreted with some caution: they reflect patients' perceptions of medical care, not doctors' actual behaviour or intentions. This was a preliminary study, which relied upon a simple questionnaire and a single item rating of satisfaction. Patients' satisfaction ratings are known to vary according to how the question is asked, and different measures may produce different results. Satisfaction can also be influenced by factors such as current health status or expectations, which were not measured. Further research in different settings, and including additional measures would be useful.

The high level of dissatisfaction reported in the present study may reflect the recruitment setting: the views expressed may not apply to different health care settings and systems. In health care systems where patients pay for treatment, medical care may be

experienced differently and viewed more favourably: for example, dissatisfaction appears to be somewhat less widespread among American CFS patients (Twemlow et al., 1997). Similarly, patients who are satisfied with the support and advice given in primary care may simply not present to specialist settings. Those who are referred to specialist settings tend to have severe fatigue, marked disability and strongly held physical illness attributions (Euba, Chalder, Deale & Wessely, 1996). Such patients can be genuinely difficult for doctors to diagnose and manage and their perceptions of medical care may reflect these complications.

Negative perceptions could also be explained by rushed consultations, which fail to adequately address patients concerns, fears and misinterpretations; lack of education about CFS among doctors; or conflicting beliefs about CFS. In the present study, all patients attributed their illness to a physical cause, but many doctors believe CFS to be psychological in origin (Ridsdale et al., 1994). Disagreement over the nature of the illness can produce a therapeutic stalemate and lead to dissatisfaction on both sides. Dissatisfaction may also result from a mismatch between patients' and doctors' expectations about the consultation. Patients with idealised expectations of medical care are more likely to express dissatisfaction than those whose expectations are low (Twemlow et al., 1997). This in keeping with the finding in the present study that satisfied patients were more likely to state that they did not expect their doctors to cure CFS. Patients who do expect a cure are likely to become rapidly disenchanted. Similarly, doctors who expect to be able to diagnose and treat patients may feel that they have little to offer those who present with an ambiguous condition that has no ready treatment. However, although many patients in the present study were critical of the paucity of treatment, this was not associated with dissatisfaction. Overall, the findings suggest that medical care was evaluated less on the ability (or otherwise) of doctors to treat CFS, and more on their interpersonal and informational skills.

Just under half the patients reported receiving a physical diagnosis (such as multiple sclerosis or arthritis) for their symptoms that later proved to be misleading or wrong, but this was not associated with dissatisfaction. In contrast, a similar proportion reported being given a psychiatric diagnosis for their symptoms, which was unacceptable to them and associated with dissatisfaction. Patients' comments suggested that psychiatric diagnoses were rejected, either because they were interpreted as meaning that symptoms were imagined or factitious, or because patients felt that doctors believed *all* their symptoms were caused by depression or anxiety. This highlights the stigma associated with psychiatric diagnoses and the value of sensitivity: doctors may intend a psychiatric diagnosis as an

etiologically neutral observation, but patients often hear it very differently, and rejection of the diagnosis may lead to treatable symptoms being overlooked or minimised. It may help to be explicit in explaining to patients that a psychiatric diagnosis can be made as a consequence of, or in combination with the diagnosis of CFS, rather than being an alternative (Sharpe, 1998).

Many patients perceived doctors as dismissive, skeptical or openly disbelieving. Patients with physical symptoms that are subjective, non-specific and of uncertain provenance may be especially sensitive to disbelief (actual or inferred). For example, elsewhere, CFS patients have described encountering such attitudes in a wide variety of social interactions, involving not just doctors, but families, friends and employers (Ware, 1993). However, perceived disbelief in the medical encounter has particular salience: without medical legitimisation, patients may be denied access to support, treatment and the rights and benefits of the sick role. Also, patients who think their doctor does not believe them often feel they have to prove they are really ill, which can make it impossible to get better (Hadler, 1996).

Just under half the patients in the study perceived their GP or hospital doctor as having been the source of greatest help to them: they describe these doctors as providing regular monitoring and support, making or acting on suggestions, arranging investigations, making a prompt diagnosis and being knowledgeable about CFS. However, there was also a prevailing view (most common among dissatisfied patients) that insufficient guidance was available, and that doctors were not knowledgeable about CFS. Evidence from chronic pain patients suggests that patients who feel they have not received enough information from doctors become more anxious about the nature and outcome of their illness, suffer more distress and want more investigations (Kouyanou, Pither & Wessely, 1997; Deyo & Diehl, 1986). There may well be a need for doctors to receive better education on how to give specific, individualised evidence based advice.

The views expressed in the present study are similar to those held by CFS patients recruited from non-medical settings in the UK and Australia (Ax et al., 1997; Broom & Woodward, 1996; Cooper, 1997; Woodward et al., 1995). Although many were critical of the quality of medical care, access to a supportive doctor who believed in the patient's symptoms was highly valued. The main difference is that in the present study men were just as likely as women to be dissatisfied with medical care, and to describe unhelpful or upsetting experiences. This discrepancy could reflect the larger percentage of men in the present study, or differences in recruitment settings — perhaps dissatisfied men are more likely to present to specialist clinics than to join patient associations.

Dissatisfaction with the attitudes, knowledge and informational skills of doctors has also been described by patients with conditions analogous to CFS: fibromyalgia, repetition strain injury, medically unexplained disability and chronic pain (Davison, Sharpe, Wade, & Bass, 1999; Ewan, Lowy, & Reid, 1991; Henriksson, 1995; Kouyanou et al., 1997; Reid, Ewan, & Lowy, 1991). Such views appear significantly less common among patients whose symptoms have a clearcut physical basis (Kouyanou, Pither, Rabe-Hesketh, & Wessely, 1998). It seems that whatever the intentions of doctors, many patients with subjective, ambiguous physical symptoms of uncertain aetiology experience medical care as unsatisfactory, confusing or distressing. This suggests a need for better communication and better education of doctors in the diagnosis and management of CFS and allied conditions.

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