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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

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