

Chronic Fatigue Syndrome: Overcoming the Attitudinal Impasse

E. Stein, MD FRCP(C)

SUMMARY. Context: Patients with Chronic Fatigue Syndrome and their physicians are often in conflict about the etiology and treatment of CFS.

Objectives: 1. Survey the literature regarding physician's attitudes towards CFS; 2. Examine the contributing factors to physician's attitude towards the disorder; and 3. Suggest solutions.

Data Sources: The relevant medical and psychological literature (years 1988-2000) was searched using the search term "Chronic Fatigue Syndrome." This was supplemented with papers from the bibliographies of the retrieved papers, additional related literature, and clinical experience.

Data Synthesis: Forty-six to ninety percent of GPs accept CFS as a discrete clinical entity and 30-82% are willing to make the diagnosis in qualifying patients.

Conclusions: CFS is a heterogeneous, multifactorial host response disorder that is inadequately described by the biomedical model. Despite substantial evidence of multisystemic physical abnormality in CFS, the lack of pathognomic tests and the female gender predominance cause

E. Stein is Staff Specialist in Psychiatry, Community Adolescent Team, The Junction, New South Wales. He is also Lecturer in Psychiatry, University of Newcastle, Callaghan, New South Wales.

Address correspondence to: E. Stein, c/o Community Adolescent Team, 36 Kenrick Street, The Junction, NSW, 2291 Australia (E-mail: aupsynd@bigpond.com).

In memory of Dr. Naomi I. Rae Grant

The author would like to acknowledge the Collaborative Pain Research Unit, University of Newcastle and Allison Hunter Memorial Foundation.

[Haworth co-indexing entry note]: "Chronic Fatigue Syndrome: Overcoming the Attitudinal Impasse." Stein, E. Co-published simultaneously in *Journal of Chronic Fatigue Syndrome* (The Haworth Medical Press, an imprint of The Haworth Press, Inc.) Vol. 8, No. 3/4, 2001, pp. 53-61; and: *Innovations in Chronic Fatigue Syndrome Research and Clinical Practice* (ed: Roberto Patarca-Montero) The Haworth Medical Press, an imprint of The Haworth Press, Inc., 2001, pp. 53-61. Single or multiple copies of this article are available for a fee from The Haworth Document Delivery Service [1-800-342-9678, 9:00 a.m. - 5:00 p.m. (EST). E-mail address: getinfo@haworthpressinc.com].

some physicians to continue to treat CFS as a psychosocial disorder. This leads to conflict between patients and physicians. CFS challenges physicians to think beyond current disease models, to tolerate diagnostic and therapeutic uncertainty, and to work collaboratively with patients rather than taking the role of expert. [Article copies available for a fee from The Haworth Document Delivery Service; 1-800-342-9678. E-mail address: <getinfo@haworthpressinc.com> Website: <<http://www.HaworthPress.com>> © 2001 by The Haworth Press, Inc. All rights reserved.]

KEY WORDS. Attitudes, etiology, diagnosis

INTRODUCTION

Despite a large and growing evidence of immune, endocrine, autonomic and cognitive dysfunction in CFS, a precise understanding of CFS etiology and mechanism has not yet been reached (1). Inadequate definition, the heterogeneous presentation of patients with CFS and physician's discomfort with disorders which do not conform to a linear biomedical model have contributed to uncertainty among physicians as to the legitimacy of CFS as a discrete medical entity. Many physicians continue to formulate and treat CFS as a psychosocial disorder. Patients, on the other hand, believe their problems to be primarily of physical origin and are dissatisfied with treatment that does not address physical issues. The objective of this paper is to review the literature about physician's attitudes towards CFS, to examine the contributors to these attitudes and to suggest solutions to the current impasse

Quantitative data was gathered through a search of the literature (MEDLINE and PSYCHLIT 1988-2000) using the search term "Chronic Fatigue Syndrome" in it. All abstracts ($n > 1500$) were searched. The full text of all relevant papers was retrieved. The bibliographies of the retrieved papers and the full holdings of the *Journal of Chronic Fatigue Syndrome* (not in Medline) were searched by hand. This paper is not intended as a thorough review of the etiology or treatment of CFS but does include relevant examples to highlight useful conceptions and some of the common misconceptions about the disorder.

ACCEPTANCE OF CFS

The five published surveys of physician's attitudes towards CFS are summarized in Table 1. A sizable minority (10-54%) of GPs responding

TABLE 1. GPs acceptance of CFS

Study	Country	Selection method	Response rate (%)	Number of responding GPs	% Accepting existence of CFS	% Comfortable/able to diagnose CFS
Ho-Yen & McNamara 1991 (2)	2 counties, Scotland	total sample	91	178	71	n/a
Denz-Penhey et al. 1993 (3)	Otago New Zealand	total sample	85	97	90	69.5
Woodward et al. 1995 (4)	Canberra, Australia	solicited from GP branch	unclear	20	n/a	30
Fitzgibbon et al. 1997(5)	Ireland	random	72	118	58	82
Steven et al. 2000 (6)*	Australia	stratified by state	77	1615	46	66 (made dx in past year)

* survey completed in 1995 but not reported until 2000

n/a—not reported

to the surveys are uncomfortable with the concept of CFS as a clinical entity. As few as thirty percent of responding GPs were willing to diagnose CFS in patients meeting the criteria. It is likely that among the survey non-respondents acceptance of CFS is even lower. The acceptance rates may not seem inordinately low. However, if other disorders of unknown etiology (e.g., multiple sclerosis, rheumatoid arthritis) were substituted for CFS non-acceptance by even a small percentage of practicing GPs would be unacceptable.

Of the physicians who remain reluctant to make the diagnosis of CFS, some argue that it is unethical to diagnose a disorder which cannot be treated (3) while others worry that a diagnosis of CFS will encourage illness behavior that will perpetuate disability (5). There is no research evidence to support this concern. In fact the opposite may be true. Patients without a firm diagnosis may seek further opinions (3). Unfortunately some physicians shy away from diagnosing and treating CFS in order to avoid controversy or scrutiny from their peers (3).

PATIENT-PHYSICIAN CONFLICT

At the core of the conflict between physicians and patients lies disparate views about the etiology of CFS. Most patients cite physical factors

as the primary cause of their illness (6). Physicians, on the other hand, feel uncomfortable assuming a physical cause when no precise physical etiology has been established. Dissatisfaction and conflict between patients and their physicians is more common with CFS than with other chronic medical disorders (7). Patients with CFS report that their concerns are not taken seriously and that they are not given the emotional or informational support that they need (7-9). Physicians express frustration with the quality of care they provide patients with CFS (4). They report that patients with CFS take up extra time during consultations (1) and are "difficult" to treat (10,11). This is especially true for patients who have self-diagnosed with CFS (9,10). Although the conflict between patients with CFS and their physicians is predicated upon the lack of legitimacy of CFS, both physicians and patients tend to blame each other.

CFS IS NOT YET WELL DEFINED

Part of the problem arises from inadequate definition of CFS. There are four definitions currently in use. Each is the result of clinical experience and consensus and as such reflects the assumptions of the creators. For example, the most stringent criteria (CDC 1988) require both physical symptoms and signs in addition to disabling, prolonged fatigue (12) whereas the least stringent (Oxford, Australian) require neither (13,14). The most widely used definition (CDC 1994) for CFS requires the concurrent expression for at least 6 months of fatigue that substantially limits functioning and is accompanied by at least four of the following symptoms: post-exertional fatigue, muscle or joint pain, cognitive changes, axillary or cervical lymphadenopathy, headache, sore throat and sleep disturbance (15). However, most patients report additional symptoms which are not included in any of the above definitions, e.g., visual blurring, clumsiness, parasthesias, paralysis, nocturia, nausea, orthostatic intolerance, alcohol intolerance, gastrointestinal and sicca symptoms. (13,16-18)

A factor analysis of the largest CFS patient set yet reported (n = 1573) confirms heterogeneity. CFS consists of three different independent factor groupings: immune/general, cognitive and musculoskeletal (19). Each of these three factor groups differentiated between defined CFS patients and controls. A fourth factor grouping of emotional/psychiatric symptoms failed to discriminate. This suggests that the current definitions need to be revised to: include more discriminating symp-

toms, consider multiple symptom dimensions and to decrease the emphasis currently given to psychiatric disorder.

CFS IS A MISLEADING LABEL

Many argue that the label "Chronic Fatigue Syndrome" contributes to the disorder's lack of legitimacy because it emphasizes only one symptom "fatigue," which is such a common and non-specific symptom. The name fails to convey that the mental and physical fatigue in CFS are not substantially relieved by rest nor that exertion worsens symptoms. The lack of mention of physical signs and symptoms in the label allows the inclusion of a very heterogeneous group of less severely ill patients to be considered under the rubric of CFS. As a result many research hypotheses and findings may not pertain to patients with tightly defined CFS who have multisystemic involvement.

CFS AND THE MEDICAL MODEL

The medical model encourages physicians to examine patients for signs and symptoms, make a diagnosis and then implement diagnosis based treatment. Although not explicit in the medical model, it is usually assumed that specific genetic or external factors result in specific clinical presentations in a linear fashion. Disorders such as CFS which are non-specific host responses to unknown or multiple stressors fit poorly into a biomedical model. It cannot be overemphasized that there is nothing inherent in the medical model that makes it ill suited to conditions such as CFS. Indeed, bio-psycho-social formulations for all medical presentations are encouraged. However, these holistic formulations are difficult to implement in a busy general medical practice (21).

Early skeptics of the validity of CFS (then referred to as benign myalgic encephalomyelitis) cite the female preponderance of sufferers and the lack of definitive physical findings as evidence that the disorder was hysterical in nature (21). Similar logic informs recent papers espousing a psychosocial etiology for CFS. The thesis of this paper is that absence of evidence does not constitute evidence of absence. Medical history is replete with incorrect assumptions of psychological etiology prior to technology becoming available to prove otherwise. Schizophrenia, multiple sclerosis, peptic ulcer disease, inflammatory bowel disease, asthma, tuberculosis and myasthenia gravis are only a few examples.

PHYSICIAN'S DISCOMFORT WITH UNCERTAINTY

It is a puzzle why so many physicians are reluctant to admit that CFS is a valid and debilitating disorder that has not yet been adequately described. Up to 80% of patients presenting to general practitioners cannot be given a diagnostic label that fully accounts for their symptoms (22,23). Being uncertain of diagnosis or treatment is certainly unsettling for physicians and can lead to feelings of helplessness and incompetence. The greater the discomfort, the more likely physicians are to jump to conclusions based on partial evidence. This is especially true when the incorrect conclusions are supported by colleagues held in high esteem. The pressure from health service funders for rapid diagnosis and treatment places additional pressure on physicians to make premature and simplistic conclusions.

OVERCOMING THE IMPASSE

A respectful and collaborative approach to CFS management requires physicians to maintain a healthy skepticism of what they have learnt. Current medical knowledge cannot adequately explain CFS. When patients present with symptoms that seem "impossible" or "bizarre," physicians must be willing to question both their patients and their medical knowledge. Instead of assuming that the patient is mistaken or neurotic, physicians must try to explain what they see and resist the temptation of simplistic explanations even when they come from reputable sources.

In many cases, frustrations within the doctor-patient relationship are a result of conflicting views about CFS etiology and treatment. It is important to remember that such conflicts are relational or contextual issues and not necessarily suggestive of either patient or physician psychopathology.

Management should be aimed at supporting healthy body functioning and treatment of symptoms that contribute to morbidity. Each symptom is understood in the context of its function and its relation to the rest of the body. Some of the ancillary symptoms found in CFS are treatable, e.g., postural hypotension (24), hypocortisolemia (25), psychiatric disorder, irritable bowel syndrome (26), bacterial infection (27) and irritable bowel symptoms (26). Although treating concomitant disorders rarely "cures" CFS, it may decrease patient morbidity.

Because there is no gold standard for CFS treatment, physicians and patients must share the responsibility for information gathering and monitoring of the patient's progress. Each patient becomes an N = 1 experiment in which the observations of both patient and physician inform critical decision making. Asking patients to keep daily symptom diaries and then reviewing symptom ratings before and after treatment trials is a powerful way of assessing outcome. Few patients will choose to pursue a harmful or ineffective treatment in the face of their own conflicting evidence.

CONCLUSION

The medical profession is at a crossroads. Approaching a problem repeatedly in the same manner generally leads to predictable results. If physicians continue to assume patients with CFS are psychologically disturbed just because medical technology cannot yet explain the physical aspects of their disorder, it is likely that the current discontent between patients with CFS and physicians will continue. Alternatively, accepting ignorance as an inevitable and challenging aspect of medicine will enable physicians to work with patients to discover the causes and mechanisms of CFS and may herald a new approach to multifaceted disorders such as CFS that are not yet well understood.

REFERENCES

1. Komaroff AL. The biology of chronic fatigue syndrome. *American Journal of Medicine* 2000; 108: 169-171.
2. Ho-Yen DO, McNamara I. General practitioner's experience of the chronic fatigue syndrome. *British Journal of General Practice* 1991; 41 (349): 324-326.
3. Denz-Penhey H, Murdoch JC. General practitioners acceptance of the validity of chronic fatigue syndrome as a diagnosis. *New Zealand Medical Journal* 1993; 106 (953): 122-124.
4. Woodward RV, Broom DH, Legge DG. Diagnosis in chronic illness: disabling or enabling—the case of chronic fatigue syndrome. *Journal of the Royal Society of Medicine* 1995; 88 (6): 325-329.
5. Fitzgibbon EJ, Murphy D, O'Shea K, Kelleher C. Chronic debilitating fatigue in Irish general practice: a survey of general practitioner's experience. *British Journal of General Practice* 1997; 47 (423): 618-622.
6. Stever ID, McGrath B, Qureshi F, Wong C, Chern I, Fern-Rowe B. General Practitioner's beliefs, attitudes and reported actions towards chronic fatigue syndrome. *Australian Family Physician* 2000; 29 (1): 80-85.

7. Sharpe M, Hawton K, Simkin S, Surawy C, Hackmann A, Klimes I et al. Cognitive behavior therapy for the chronic fatigue syndrome: a randomized controlled trial. *BMJ* 1996; 312 (7022): 22-26.
8. Twemlow SW, Bradshaw SL, Jr., Coyne L, Lerma BH. Patterns of utilization of medical care and perceptions of the relationship between doctor and patient with chronic illness including chronic fatigue syndrome. *Psychological Reports* 1997; 80 (2): 643-658.
9. Ax S, Gregg VH, Jones D. Chronic fatigue syndrome: sufferer's evaluation of medical support. *Journal of the Royal Society of Medicine* 1997; 90 (5): 250-254.
10. Green J, Romei J, Natelson BH. Stigma and chronic fatigue syndrome. *Journal of Chronic Fatigue Syndrome* 1999; 5 (2): 63-76.
11. Scott S, Deary I, Pelosi AJ. General practitioner's attitudes to patients with a self diagnosis of myalgic encephalomyelitis. *BMJ* 1995; 310 (6978): 508.
12. Sharpe M, Mayou R, Seagroatt V, Surawy C, Warwick H, Bulstrode C et al. Why do doctors find some patients difficult to help? *Q J Med* 1994; 87 (3): 187-193.
13. Holmes GP, Kaplan JE, Gantz NM, Komaroff AL, Schonberger LB, Straus SE et al. Chronic fatigue syndrome: a working case definition. *Annals of Internal Medicine* 1988; 108 (3): 387-389.
14. Lloyd AR, Hickie I, Boughton CR, Spencer O, Wakefield D. Prevalence of chronic fatigue syndrome in an Australian population. *The Medical Journal of Australia* 1990; 153: 522-528.
15. Sharpe MC, Archard LC, Banatvala JE, Borysiewicz LK, Clare AW, David A et al. A report—chronic fatigue syndrome: guidelines for research. *Journal of the Royal Society of Medicine* 1991; 84: 118-121.
16. Fukuda K, Straus SE, Hickie I, Sharpe MC, Dobbins JG, Komaroff A et al. The chronic fatigue syndrome: a comprehensive approach to its definition and study. *Annals of Internal Medicine* 1994; 121 (12): 953-959.
17. Komaroff AL, Buchwald D. Symptoms and Signs of Chronic Fatigue Syndrome. *RID* 1991; 13 (Suppl 1): S8-S11.
18. Friedberg F, Dechene L, McKenzie MJ, Fontanetta R. Symptom patterns in long-duration chronic fatigue syndrome. *Journal of Psychosomatic Research* 2000; 48 (1): 59-68.
19. Smith AP, Borysiewicz L, Pollock J, Thomas M, Perry K, Llewelyn M. Acute fatigue in chronic fatigue syndrome patients. *Psychological Medicine* 1999; 29 (2): 283-290.
20. De Becker P, McGregor NR, De Meirleir K. A factor analysis study of symptoms in 1573 patients with chronic fatigue syndrome. *Vrije Universiteit Brussel*, 2000.
21. Straus SE. Chronic fatigue syndrome. *BMJ* 1996; 313 (7061): 831-832.
22. McEvedy CP, Beard AW. Royal Free Epidemic of 1955: A reconsideration. *BMJ* 1970; 1: 7-11.
23. Kroenke K, Mangelsdorff AD. Common symptoms in ambulatory care: incidence, evaluation, therapy, and outcome. *American Journal of Medicine* 1989; 86 (3): 262-266.
24. Bridges-Webb C, Britt H, Miles D, Neary S, Charles J, Traynor V. Morbidity and treatment in general practice in Australia 1990-1991. *Medical Journal of Australia* 1992; 157: S1-S53.

25. Bou-Holaigah I, Rowe PC, Kan J, Calkins H. The relationship between neurally mediated hypotension and the chronic fatigue syndrome. *JAMA* 1995; 274 (12): 961-967.

26. Cleare AJ, Heap E, Malhi GS, Wessely S, O'Keane V, Miell J. Low-dose hydrocortisone in chronic fatigue syndrome: a randomised crossover trial. *Lancet* 1999; 353 (9151): 455-458.

27. Paterson WG, Thompson WG, Vanner SJ, Faloon TR, Rosser WW, Birtwhistle et al. Recommendations for the management of irritable bowel syndrome in family practice. IBS Consensus Conference Participants. *CMAJ* 1999; 161 (2): 154-160.

28. Nicolson GL, Nasralla MY, Haier J, Irwin R, Nicolson NL, Ngwenya R. Mycoplasmal infections in chronic illnesses: fibromyalgia and chronic fatigue syndromes, gulf war illness, HIV-AIDS and rheumatoid arthritis. *Medical Sentinel* 1999; 4 (5): 172-191.