

Patient management of post-viral fatigue syndrome

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SUMMARY. A case definition for post-viral fatigue syndrome is proposed within which various subgroups of patients exist. Any one treatment may not apply to all the subgroups. In particular, patients' experiences do not show that avoidance of exercise is maladaptive. It is proposed that the recently ill often try to exercise to fitness whereas the chronically ill have learnt to avoid exercise. Recovery is more likely to be achieved if patients learn about their illness and do not exhaust their available energy.

Introduction

THE management of post-viral fatigue syndrome is a contentious subject but the differences in management may arise because different groups of patients are being discussed. There is no general agreement on an acceptable case definition for this condition,¹ and before limited research findings² are extrapolated into a model for management, it seems sensible to establish that the same type of patient is being considered.

This paper has been written in response to a discussion paper in the *Journal*.³ It is entitled 'patient management' as it is based on the collective experiences of patients and because the patient's active participation is the most important component of the proposed management strategy.

Case definition

The Centres for Disease Control in the USA have suggested criteria for post-viral fatigue syndrome⁴ which require the patient to have been ill for at least six months and the active exclusion of some 50 conditions, including entities such as malignancy and autoimmune disease. These criteria have been modified by a group of Australians⁵ who added the requirement that abnormal cell-mediated immunity should be present. One possible explanation for variations in diagnostic criteria in different parts of the world is that the causative agent differs — Epstein-Barr virus is believed to be the causative agent in the USA,⁴ whereas in the UK enterovirus infection appears dominant.⁶ With an Epstein-Barr infection it would be reasonable to have a six month cut-off period and expect pyrexia, lymphadenopathy, pharyngitis and abnormalities in T cells. However, in a recent Scottish study of patients at presentation,⁷ it was found that 55% had been ill for three to six months. A six month cut-off period would have resulted in an unnecessary delay in making a diagnosis and added to the stress of the patients. It is also unreasonable to attempt to exclude 50 causes for a similar illness; it is better to exclude only those causes that are obvious after taking a detailed history and performing a clinical examination. Suggested diagnostic criteria for the UK are given in Figure 1.

Definition

The patient with post-viral fatigue syndrome:

1. Has had generalized, relapsing fatigue exacerbated by minor exercise causing disruption of usual daily activities for at least three months.
2. Complains of prominent disturbance of concentration and/or short term memory impairment.
3. Has no other obvious, organic causes for a similar syndrome.

Supporting evidence (at least four items from sections A, B and C)

A. History

Patient well before illness
An initiating viral illness (clinical description/viral serology)
Myalgia
Gastrointestinal disturbance
Headaches
Depression
Tinnitus
Paraesthesiae
Sleep disturbance
Cardiovascular complaints
Adverse effect of alcohol
Adverse effect of heat

B. Clinical

Lymphadenopathy
Localized muscle tenderness
Pharyngitis

C. Laboratory

Evidence of viral infection
Abnormalities in immune function

Figure 1. Suggested diagnostic criteria for post-viral fatigue syndrome in the UK.

Patient sub-groups

The symptoms of patients suffering from post-viral fatigue syndrome are diverse.^{8,9} While a disease is being defined, it is useful to document the spectrum of presentation. However, when considering management, especially when this is supportive rather than curative, it is sensible to establish sub-groups of patients with different characteristics.

Age

The age of a patient suffering from post-viral fatigue syndrome may influence the prognosis. An estimate of the mean age of patients can be made from two studies.^{7,9} The mean age of patients presenting with symptoms to a general practitioner or hospital doctor was 34.6 years⁷ whereas among patients referring themselves to one of the myalic encephalomyelitis self-help groups the mean age was 42.6 years.⁹ This difference may represent progress of the disease. Even though the selection and composition of patients in these two studies was different, analysis of the age groups may provide useful information on prognosis (Table 1). It would appear that in patients aged under 30 years the illness is less likely to be chronic than in patients aged 50 years or more.

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Table 1. Age of patients at presentation⁷ and at self-referral.⁹

Age (years)	Number (%) of patients	
	Presenting (n=381)	Self-referring (n=400)
0-19	43 (11)	14 (4)
20-29	110 (29)	57 (14)
30-39	89 (23)	110 (28)
40-49	88 (23)	92 (23)
50-59	37 (10)	79 (20)
60+	14 (4)	48 (12)

n = total number of patients.

Sex difference

There is a considerable difference in the sex ratio of patients at presentation and self-referral. At diagnosis of post-viral fatigue the sex ratio is approximately equal — 204 females to 177 males (1.2:1.0).⁷ However, self-referral studies show a preponderance of females — 307 females to 93 males (3.3:1.0)⁹ and 216 females to 42 males (5.1:1.0).¹⁰ It may be that men who are chronically ill are reluctant to take part in such studies or that women may be more prone to developing post-viral fatigue syndrome.

Length of illness

In self-referral studies of the post-viral fatigue syndrome the illness had lasted for less than two years in 35%⁹ and 24%¹⁰ of patients. However, a study of patients at presentation showed 91% were in this category.⁷ By combining the data from the self-referral studies^{9,10} the wide range in the length of illness can be appreciated: less than two years, 32% of patients; three to 10 years, 44%; 11–20 years, 14%; and more than 20 years, 9%.

Muscle pain

A complaint of fatigue may be a result of a 'central' mechanism or muscle pain. In self-referral studies 55%⁹ and 83%¹⁰ of patients had muscle pain. The limit of activity in those with muscle pain naturally relates to the severity of the pain; those without muscle pain probably limit activity because of a 'central' sensation of fatigue. This difference is of considerable importance in devising ways of helping people to plan their activities.

Immunological abnormalities

In some studies, immunological abnormalities were common,⁵ but were less so in others.¹ These differences may be due to the causative organism or they may reflect the body's immune response. The subgroup of patients with immunological abnormalities may have a prolonged illness.¹¹

Other factors

There are many common symptoms which may justify a different approach to management. The more important symptoms may be individually defined, for example dysrhythmias, or grouped by system, for example central nervous, gastrointestinal or cardiovascular.

Approaches to management

Even today some clinicians do not believe that patients presenting with symptoms of post-viral fatigue syndrome are ill.^{8,10} However, the term malingering cannot be applied to the majority of individuals as they will previously have been well and active. Nevertheless, not all patients suffering from persistent fatigue will have post-viral fatigue syndrome — less than 5% have the syndrome and two-thirds have clinically active psychiatric disorders.¹² How should a general practitioner

approach this problem? First, it is important to reassure patients that they are suffering from something, and one should then attempt to establish a diagnosis using the criteria in Table 1. Patients find a diagnosis of post-viral fatigue syndrome more helpful than 'I know that you are ill but I do not know what is wrong'. In the latter case a referral would seem appropriate and in either case further investigations may lead to another diagnosis. Nevertheless, a diagnosis of post-viral fatigue syndrome is based on a firmer foundation than many diagnoses of a 'viral illness'.

Having made a diagnosis of post-viral fatigue syndrome the general practitioner will have to decide which patients should be referred for psychiatric or specialist assessment. This will depend on the practitioner's aptitude and the amount of time he or she has available. To achieve good progress patients suffering from the syndrome require a considerable amount of time with a doctor, probably a total of 45–90 minutes over four to eight weeks.

Approaches to treatment

It has been suggested that a new approach to the treatment of patients with post-viral fatigue syndrome would be the adoption of a cognitive behavioural model.³ However, many stages of this model appear to be based on patients who have been ill for more than five years rather than those who have been ill for between three months and two years (Table 2). Those who are chronically ill have recognized the folly of the approach which is taken by the recently ill and, far from being maladaptive, their behaviour shows that they have insight into their illness. The model, which has been claimed as a new approach³ is no more than the conventional view — patients have been told for decades to 'get out and exercise' or 'go back to work'. Indeed, the truly new approach is that of moderating activity. This approach is based on patients' experiences that of all treatments, rest is by far the most helpful.⁹

Proposed model for management

My approach to management has been described in detail elsewhere.⁸ The success of the approach depends on active participation by the patient, although specialist help is useful in making the diagnosis and monitoring progress. Many patients

Table 2. Stages in Wessely's³ proposed model for post-viral fatigue syndrome compared with patients' experiences.

Stages of proposed model	Patients' experiences	
	Recently ill ^a	Chronically ill ^b
1. Acute illness accompanied by period of inactivity	No. Usually restart work/activity too soon	No. Often history of 'ignoring' initial illness
2. Fatigue on exertion limits further activity	No. Cannot understand fatigue, keep active	Yes. Recognition that fatigue is a warning light
3. Never pursue activity until symptoms subside	No. Many attempts to exercise to recovery	Yes. Recognition that pursuing activity makes illness worse
4. Unfitness results in symptoms after only little activity	Perhaps. May also be due to worsening of disease	Yes. Unfitness in chronic illness, but also symptoms from worsening of disease

^a Three months to two years. ^b More than five years.

seen in hospital have been ill for two to six years and during this time the general practitioner will have provided treatment and dealt with most of the patient's social and coincident medical problems. Patients should be seen every four to eight weeks by their general practitioner or in hospital.

Doctors have to accept that patients are ill, identify their problems, encourage them to help themselves and offer support throughout the illness. A good relationship between the doctor and the patient is essential.

Patients suffering from post-viral syndrome must realize that they are ill and that there are considerable social and emotional pressures on them. They must become immune to the bantering of friends and relatives and must stop looking for instant cures. Patients should try to learn about their illness and how it affects them rather than wasting energy in anger and frustration. They should keep a daily record of their symptoms and activities. This provides a sense of direction and allows progress to be monitored. It is also an emotional safety valve. Patients must also learn to control their activities. They must decide whether they are going to expend their energy on work, social activity, exercise or their family. They will not be able to do all of these. They should remember that sleep is curative.

Most alternative therapies are not harmful. Many exploit the patient, but some may be beneficial. Doctors have a duty to inform patients about these therapies and patients have the right to choose. Nevertheless, after a trial period of six to 10 weeks, patients should be honest with themselves about the results of treatment.

In the first years of illness, the patient's family is an important asset. Problems such as the development of food allergies or unemployment are sufficient to test the strongest relationships and it is reassuring that many families are able to meet these challenges. However, it is understandable that divorce or separation are common among those with long-standing illness. Following such major events, it may be difficult for the general practitioner to determine whether the patient's behaviour is normal. The general practitioner should also be aware that patients often develop psychiatric disorders as a result of chronic ill health. One method of monitoring the development of such disorders is to use a questionnaire to detect anxiety or depression.^{13,14}

As with other chronic illnesses, the best results are obtained when the doctor and patient develop a mutual understanding of each other's position.

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