The report of the Chief Medical Officer's CFS/ME working group: what does it say and will it help?

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ABSTRACT – Chronic fatigue syndrome (CFS) sometimes known as myalgic encephalomyelitis or encephalopathy (ME) has long been a controversial topic. This year has seen the publication of a report from an independent working party set up by the UK Chief Medical Officer (CMO) to make recommendations for the management of the condition. The report makes a number of general recommendations about the provision of appropriate care and services. The more controversial issues of what to call the illness, the nature of the illness and what treatment should be recommended are all addressed, but in the form of compromise rather than resolution. To the extent that this report is a step towards highlighting the needs not only of patients with CFS but the larger group of patients with symptom-defined conditions, it is to be welcomed. As a guide to management it raises as many questions as it answers. Much remains to be resolved before guidance that is both evidence based and acceptable to all parties is achieved.

KEY WORDS: chronic fatigue syndrome, CMO, CBT, graded exercise, patient preference, randomised trials, evidence-based medicine, medically unexplained symptoms

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Chronic fatigue syndrome (CFS) describes a symptom-defined syndrome with fatigue, typically exacerbated by exertion as the cardinal symptom. Muscle aches, poor concentration and unrefreshing sleep are commonly associated[1].

CFS has long been a controversial subject. Central to the controversy is the question of whether an illness can be both genuine and psychiatric. This controversy has been played out repeatedly not only within the individual doctor-patient relationship but also in the social and political arena. Medical reportage has been widespread, if often uninformative[2,3].

Patients' organisations have been notably effective in lobbying parliament. Largely as a result of this political pressure, in 1998 Dr Kenneth Calman, the then UK Chief Medical Officer, took the unusual step of commissioning a special working group to report to him on the most effective methods of treatment and management for this condition.

The working group was not the first to provide a report in the UK. The Royal Colleges of Physicians, Psychiatrists and General Practitioners, published a report in 1996[4]. However, the newly proposed working group was novel in that it was composed not only of medical experts but also of patients and representatives of patients' organisations. The committee submitted a report to the CMO, by that time Professor Sir Liam Donaldson. The report was finally published in January 2002[5].

The committee process was stormy and marked by resignations[6]. Five professional members resigned because they felt the recommendations had departed from the evidence base and were biased towards a biomedical rather than biopsychosocial perspective. Two patient organisation representatives resigned because they felt that they could not endorse the recommendations of graded exercise therapy (GET) and cognitive behaviour therapy (CBT).

Given this background, an initial reading reveals that many of the recommendations of the final report are surprisingly uncontroversial. For example, it calls for good clinical care carried out in partnership with the patient, for care commensurate with health needs, and for involvement of the patients' families. It calls for the provision of appropriate secondary and tertiary services to support primary care. It also calls for better education of health professionals and more research into all aspects of the condition.

Further examination reveals the reasons for controversy however. The first reason is as basic as what to call the illness. Researchers welcomed the name chronic fatigue syndrome (CFS) when it was introduced in 1988. This new and neutral term replaced others that embodied unproved aetiological assumptions, such as chronic Epstein-Barr virus infection and chronic Brucellosis. It also provided researchers with an operational definition that allowed the findings of studies to be compared[7]. The definition proposed proved to be too restrictive and has subsequently been simplified[1], but the term CFS has been retained. CFS has however long been disliked by patients' organisations, who regard it as

'demeaning' of their illness. The term preferred by those organisations in the UK is myalgic encephalomyelitis (or more recently myalgic encephalopathy) both abbreviated as 'ME'.

The term myalgic encephalomyelitis (ME) was introduced in a *Lancet* editorial in 1956 to describe an illness which affected staff at the Royal Free Hospital in London at the time of an epidemic of poliomyelitis[8]. It has subsequently been used by some researchers, many patients and most of the UK patients' organisations as a term for an illness that is either similar to, or a severe form of, CFS. The working party report uses both CFS and ME but declines to recommend one term over the other, preferring the compromise 'CFS/ME'. Whether this solves the issue remains to be seen. But more important than the name is the implication it carries. For many ME implies not only a 'real illness' but also a fixed and permanent disease like multiple sclerosis (MS). This is a matter of concern to those who regard the condition as potentially reversible with appropriate treatment.

An associated issue is whether CFS/ME is best regarded as a 'medical' or as a 'psychiatric' illness. This question is of course as pointless (in the sense that such a classification of illness is purely administrative and says nothing about the nature of the illness) as it is central (in so for as psychiatric conditions are often stigmatised as 'imaginary', 'blameworthy' and a sign of 'weakness'). Again, the report does not draw a conclusion, but skirts around the issue. The working party's compromise is to recommend that management should be by 'multi-disciplinary' teams. Underplaying the need for psychiatric management may avoid stigma, but for a condition with such a high rate of depression and anxiety, may ultimately result in less effective treatment for patients.

Perhaps the most controversial recommendations of the report are those that address the original brief; the choice of treatment. A high quality systematic review of all relevant randomised treatment trials was commissioned for the report and carried out by the National Health Service Centre for Reviews and Dissemination, University of York, England, and published jointly with a parallel American review from the San Antonio Evidence-Based Practice Center in Texas[9]. Despite the increasing number of randomised trials of treatments for CFS, only the non-pharmacological and rehabilitative treatments of CBT and GET emerged as having significant empirical support from reasonably high quality randomised trials.

These treatments are however unpopular amongst patient organisations, perhaps because they have been proposed and are sometimes delivered by psychiatrists or psychologists. Furthermore, some patients have reported that they have been made worse by the treatments (despite this being very rarely reported in the publications of the trials). The working party examined this issue by surveying the membership of one of the patient organisations. In this survey a substantial minority of respondents reported that CBT and GET had actually 'made them worse'. How representative this sample was of CFS patients as a whole, and what type and quality of therapy they had actually received, remains unclear. Nonetheless, this finding is a cause for concern. The report's treatment recommendations were also a compromise but probably its most uneasy one[10]. CBT and GET were recommended based on the systematic reviews. Another form of behavioural illness management called 'pacing' was also recommended but on the basis of the patient survey. The report defined pacing as 'based on the envelope theory of CFS/ME which suggests that a patent with CFS has finite energy and that the best way for them to manage their illness is to live within this envelope' (although in other places the report refers to pacing as incorporating gradual increases in activity, like CBT and GET). Whatever its definition of pacing, giving equal recommendation to treatment supported by results of trials and treatment merely reported as 'helpful' in a survey is an uneasy compromise. In practice, the choice of treatment depends on whether the condition is assumed to be 'permanent' to be adjusted to by pacing, or seen as potentially reversible and to be actively treated with rehabilitation. The evidence from trials of CBT and GET indicate substantial reversibility in a majority of participants. A report that seeks to help patients by emphasising the reality of their suffering runs the risk of ultimately failing them if it minimizes the evidence for the treatability of that suffering.

What can we say overall?

On the one hand the report is an important step forward[11]. It represents a developing, much needed dialogue to address the almost inexplicable gulf that has arisen between patients' organisations who have worked hard to further the interests of their members, and researchers and clinicians who have worked hard to develop and provide rehabilitative treatments for the same patients.

On the other hand, important controversies about the nature and management of CFS have been largely side-stepped in the report and its conclusions often read as an uneasy compromise[10]. The adoption of the name CFS/ME symbolizes this.

My own view has long been that the controversies about CFS are essentially those of a much larger, if less vocal, group of patients. That is the one-third of medical outpatients who have conditions that are defined only in terms of symptoms without the presence of what we call disease[12]. The dislike that all these patients have of 'psychiatric' names such as somatisation and of 'psychological' treatments such as CBT is unfortunate, but entirely understandable[13]. All too often patients form the view that their 'medically unexplained' somatic symptoms are being regarded by doctors as psychiatric, in the sense of being 'imagined'. The danger both for individual patient and for this report is that the understandable reaction to feeling disbelieved is to argue that one not only has a real condition but one that is a permanent and untreatable disease. As the American physician Nortin Hadler has so aptly said about the related syndrome of fibromyalgia 'If you have to prove that you are ill, you can't get well'[14].

If this report stimulates the need for clinicians and researchers to work together with patients and their representatives to improve the acceptance, not only of those patients who receive a diagnosis of CFS but also the larger number with other so-called

'medically unexplained symptoms', it will have been a most useful beginning. If the disputes, particularly those about treatability, can be resolved by well-conducted and jointly supported research studies, we will have a way forward. However, the production of this report also tells us that a genuine resolution of the disagreements about the nature and management, and between scientific evidence and patient preference, will not always be easy.

This report should help to highlight these issues and to focus the debate. But it does not fulfil its original aim of providing guidance for patient care that is both evidence based and agreed by all. That will require further work.

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