

Chronic fatigue syndrome: Labels, meanings and consequences

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Abstract

In this month's issue, we report a survey of members of the Association of British Neurologists, which asked if they viewed chronic fatigue syndrome (CFS) as a neurological condition—84% of respondents did not. This is at odds with current classification in ICD-10. We discuss the difficulties of classifying CFS and myalgic

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encephalomyelitis (ME), including historical and sociological factors, the pitfalls of the physical/psychological dichotomy and why classification matters to doctors and patients.

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In this month's issue, we report a survey of members of the Association of British Neurologists, which asked if they viewed chronic fatigue syndrome (CFS) as a neurological condition — 84% of respondents did not [1]. Conversely, the *International Classification of Diseases, 10th Revision* (ICD-10) classifies myalgic encephalomyelitis (ME) and CFS under Disorders of the Nervous System, although as our letter points out, it confusingly allows for both neurological and psychiatric coding of CFS but not ME, despite the two being synonymous in the research literature.

This is important in the context of ongoing work on the next editions of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) and ICD. To help interpret these findings and consider why illnesses may be physical and psychological rather than one or the other, we draw on the history of ME and CFS, focusing on the factors which influenced its classification as a neurological disorder and why classification matters (to patients and doctors).

The historical background to the classification of CFS

How did CFS come to be classified in the way that it is? The following factors are discussed below: the changing presentation of the disorder, the perceived primacy of medical over psychiatric diagnoses and differences between them, and socioprofessional shifts away from psychological models of illness. The social history of neurasthenia is used to further illustrate some of these factors.

ME then and now

Before the label and diagnostic criteria for CFS were introduced in 1988 in the UK, the condition was known as 'ME'. This term was first used to describe an illness outbreak amongst doctors and nurses at the Royal Free Hospital in 1955. Their presentation superficially resembled that of poliomyelitis (paresis, meningism, altered reflexes and nystagmus were recorded), though there were no cerebrospinal fluid abnormalities. 'Benign myalgic encephalomyelitis' (ME) was therefore suggested as a diagnosis for this new illness [2]. Clearly, this episode is likely to have contributed to the subsequent view of the World Health Organisation (WHO) that it should be classified as a neurological disorder. These early outbreaks of illness,

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however, were almost entirely epidemics as opposed to sporadic cases that occur today, as well as featuring different signs and symptoms.

In fact, the term ‘benign ME’ is inaccurate and misleading: its course is often not benign but disabling, and ‘encephalomyelitis’, a specific and often lethal neuropathological process, does not occur. The vernacular label ‘ME’ has long since abandoned the prefix ‘benign’ and is little used in the professional literature other than as the compound term ‘CFS/ME’ (e.g., a Pubmed search for myalgic encephalomyelitis in December 2010 yielded 5180 records, of which the first 50 include 21 titles mentioning CFS, including one that mentions CFS/ME, and none which mention ME independently).

Neurasthenia, which shares an ICD-10 code with CFS as described above, was prominent in the 19th century and had a very similar presentation. The diagnosis fell out of fashion in the 20th century and is now rare, at least in the English-speaking world. The criteria for neurasthenia (F48.0) overlap almost exactly with those for CFS (Figs. 1 and 2): one study of 100 consecutive CFS patients found that 97 fulfilled criteria for neurasthenia [3].

Primacy of medical over psychiatric diagnoses

The majority of surveyed neurologists did not view CFS as a neurological condition [1], but many doctors might hesitate in considering it a psychiatric one. In most classification systems, but even more in the informal hierarchy of what is diagnostically important, psychiatric diagnoses are trumped by medical ones. In part, this reflects a moral hierarchy instilled at medical school [4], and by society at large, that physical disease should be excluded before turning to psychiatric illness. Physicians are trained to look for the needle in the haystack, and a diagnosis of mental illness is usually the hay. It is plausible that, faced with a poorly understood chronically disabling condition, the drafters of ICD-10 would have considered medical classification first and psychiatric second.

In the political rhetoric of CFS/ME, it is often said that many diseases (the most commonly cited being neurological

- A. Self-reported fatigue which is persistent or relapsing, not resulting from ongoing exertion, not substantially relieved by rest and causing impairment of previous activities.
- B. Four or more of: impaired memory or concentration; sore throat; tender cervical/axillary lymph nodes; muscle pain; multi-joint pain; new headaches; unrefreshing sleep; post-exertion malaise.
- C. Duration of 6 months or longer.
- D. No other (medical or psychiatric) cause of chronic fatigue is found.

Fig. 1. Fukuda consensus criteria for CFS (1994).

- A. Fatigue OR complaints of bodily weakness and exhaustion after minimal effort, which is persistent and distressing.
- B. At least two of the following: muscle aches and pains; dizziness; tension headaches; sleep disturbance; inability to relax; irritability; dyspepsia.
- C. Any autonomic or depressive symptoms present are not sufficiently persistent and severe to fulfil the criteria for any of the more specific disorders in ICD-10.
- D. Excludes: (list includes G93.3 postviral fatigue syndrome).

Fig. 2. ICD-10 criteria for neurasthenia.

disorders such as epilepsy) were originally considered psychological before their true neurological nature was revealed, and this will happen with CFS/ME. This stance contrasts with the view of neurologists who took part in this survey and also depends on a selective reading of history, as there are many examples of traffic flowing both ways. There has always been a steady movement in the opposite direction, as diagnoses such as autointoxication, visceral proptosis, chronic appendicitis, floating kidneys and so on, once seen as exclusively physical in origin, were reclassified as psychiatric [5]. And such rhetoric often misunderstands that the meanings of diagnostic labels have changed over time. Hence, neurasthenia, for example, in its 19th century usage clearly referred to an organic disturbance of the peripheral nervous system, and hysteria itself, now the iconic ‘all in the mind’ illness, did not have that meaning in the same period (it was classified with other functional nervous disorders such as epilepsy, migraine and chorea).

The distinction between physical and mental illness

If ME/CFS is classified as a neurological condition, then it may seem there is little that psychosocial and behavioural treatments have to offer. But are psychological perspectives banished when an organic disease process is identified?

In fact, it is now commonly understood that comorbid mental disorders such as depression considerably worsen outcomes and disability in common disorders such as cardiovascular disease, osteoarthritis and indeed in neurology generally [6–8]. Subjective reports of stress have been shown to impact on mortality [9]; good evidence supports an association between depression and increased inflammatory cytokines [10]; and psychological interventions have been shown to improve outcomes in, for example, the incidence of angina [11].

The interrelationship between physical and mental problems supports a biopsychosocial view of illness in general and questions whether the classification of a disorder should dictate treatment. As the psychiatrist Robert Kendell observed, ‘in reality, neither minds nor bodies develop illness. Only people (...) do so and when they do both mind and body (...) are usually involved’ [12].

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