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INVITED REVIEW

The act of diagnosis: pros and cons of labelling chronic fatigue syndrome

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ABSTRACT

Background. One of the many controversies surrounding chronic fatigue syndrome (CFS) is the possible impact of the diagnostic label: is it disabling or enabling? In this paper, we discuss the pros and cons of labelling CFS.

Method. A narrative synthesis of the literature.

Results. Diagnosed CFS patients have a worse prognosis than fatigue syndrome patients without such a label. The ways in which CFS patients perceive themselves, label their symptoms and appraise stressors may perpetuate or exacerbate their symptoms, a process that involves psychological, psychosocial and cultural factors. Labels can also lead to conflicts with doctors who fear diagnosis might lead to worse outcomes. However, on the other hand, finding a label that fits one's condition can provide meaning, emotional relief and recognition, whilst the denial of the diagnosis of CFS in those who have already reached their own conclusion can be very counter productive. The act of diagnosis therefore seems to be a trade-off between empowerment, illness validation and group support, contrasted with the risk of diagnosis as self-fulfilling prophecy of non-recovery.

Conclusions. The answer to the question of 'to label or not to label' may turn out to depend not on the label, but on what that label implies. It is acceptable and often beneficial to make diagnoses such as CFS, provided that this is the beginning, and not the end, of the therapeutic encounter.

Introduction

For years, the concept of chronic fatigue syndrome (CFS), also known as myalgic encephalomyelitis (ME), has been subjected to ongoing debates between clinicians, researchers, patients, support groups and other stakeholders contesting its existence, its nature, its aetiology and its treatment. Although consensus concerning the multifactorial nature of CFS is growing (Afari & Buchwald, 2003), these conflicting views have turned CFS into a battlefield of confusion.

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One of the issues that has been addressed is the impact of the diagnosis of CFS: is it disabling because it encourages people to identify with the label of being ill, or does it allow people to legitimize their suffering, improve emotional outcome and obtain care? Empirical evidence that supports either of these views is, however, lacking. Despite a considerable amount of studies, the impact of diagnosis has not been adequately assessed in outcome research.

Here, we aim to explore the pros and cons of labelling CFS, and by implication other related medically unexplained symptoms such as fibromyalgia. It should be noted that the majority of referred statements comes from discussion papers, rather than from studies presenting

empirical support for the accounts that are made. In writing this review we were inspired by many authors, but space limitations force us to cite only the key papers (an expanded list of References can be found on the Journal's website).

Early diagnosis

Various empirical studies conducted in specialist settings seem consistent in their finding that CFS is a fairly stable condition with a poor prognosis, with only 10–20% of the patients recovering in time (Afari & Buchwald, 2003). However, recent findings suggest that the course of CFS in non-hospital settings is characterized by remission and relapse (Nisenbaum *et al.* 2003; Huibers *et al.* 2004*b*), while patients meeting broader definitions of chronic fatigue have a far better prognosis, with up to 80% of the patients recovering within 1 year (Skapinakis *et al.* 2003; Huibers *et al.* 2004*c*).

The fact that patients in an earlier stage of the illness seem to do better has led some to suggest that CFS should be diagnosed as early as possible to prevent further deterioration. But can we be certain that early diagnosis will improve the prognosis of CFS? Recent findings suggest that many fatigued subjects in non-hospital settings meet research criteria for CFS without knowing so (Euba *et al.* 1996; Huibers *et al.* 2004*a*, *d*; Solomon & Reeves, 2004). These undiagnosed CFS-like patients seem to have a more favourable prognosis than CFS patients in hospital settings, raising the question whether the absence of a formal CFS diagnosis is associated with better outcomes.

ME *versus* CFS: implications of the label

Although 'ME' and 'CFS' refer to the same condition, the two labels illustrate a deep-rooted division in the CFS community. Myalgic encephalomyelitis (ME) refers to an – empirically unsupported – medical explanation for the symptoms. The term indirectly implies that the condition is incurable, unless a medical solution is found. Many patients prefer the term ME, not in the least because a biomedical label underlines the 'realness' of their complaints. The medical and research community, however, prefers the more neutral term chronic fatigue syndrome (CFS), since this label lacks causal inferences and allows a multifactorial approach. In a recent UK study, patients labelled with CFS or ME had a worse prognosis than patients with fibromyalgia or post-viral fatigue (Hamilton *et al.* 2005). Furthermore, those with a diagnosis of ME had a worse prognosis than those with CFS, even after baseline differences were controlled for. Potential biases such as (self-) selection did not explain these differences in outcome. Apparently, the label ME itself may have an adverse effect compared to the label of CFS.

Illness perception

There is compelling evidence that a pessimistic illness perception is an important perpetuating factor in CFS. The ways in which CFS patients perceive themselves, label their symptoms and appraise stressors may perpetuate or exacerbate their physical and psychosocial dysfunction (Afari & Buchwald, 2003). Several studies found that stronger somatic attributions (assuming illness has a physical origin) or weaker psychological attributions (assuming illness has a psychological origin) predict worse outcome. Additional, although indirect evidence on the impact of illness perception comes from a recent trial in which conversion disorder patients improved when told that full recovery constituted proof of a physical aetiology, whereas non-recovery would constitute proof a psychiatric origin (Shapiro & Teasell, 2004).

Ultimately, a pessimistic illness perception can become a self-fulfilling prophecy of non-recovery. This group of CFS patients tends to view their symptoms as part of an overwhelming, mysterious, unexplainable disease that struck them out of the blue and from which they most likely will never recover. These illness expectations are often fuelled by the media, support groups (not least because support groups have an inherent bias towards those who have not recovered) and other sufferers, as we will discuss in the following section.

Psychosocial and cultural factors

CFS is a mirror of society. Since the first reports of a mysterious fatigue syndrome in the early 1980s, sociologists have depicted CFS as a post-modern illness of our time (Ware, 1999; Zavestoski *et al.* 2004). Others have noted the striking resemblance between CFS and neurasthenia, a 19th-century diagnosis that

became unfashionable and disappeared from clinical practice (Greenberg, 1990; Wessely, 1990). Today's modern society seems to dictate constant activity, speed and scheduledness. CFS patients of course cannot meet these expectancies, and in numerous first-person accounts illness is blamed on these unwelcome features of modern life. Like it or not, CFS is not simply an illness, but a cultural phenomenon and metaphor of our times.

CFS has been depicted as a *meme*, an idea about illness that evolves to spread and endure in the community, and that serves to organize distress into a meaningful narrative tolerated by the biomedical model (Ross, 1999; Aceves-Avila *et al.* 2004). Labelling physical symptoms as an illness carries the risk of the symptoms becoming self-validating and self-reinforcing, often promoted by the Internet, support groups, self-help literature and mass media. Barsky describes four mechanisms by which this process of symptom amplification is mediated (Barsky & Borus, 1999): the belief that one has a serious disease; the expectation that one's condition is likely to worsen; the sick role; and distress that comes from daily life problems and major life changes. The anguish of distress and fatigue might drive an individual to find a name and meaning to his suffering, and the label of CFS or ME might present that cathartic voice. Learning about a new disease may lead to redefinition of earlier, ill-defined symptoms into one concept of illness, heightening bodily awareness and reinforcing illness beliefs.

CFS, as with many other contested diagnoses, appears to have started from small groups and then spread along the lines of communication and exposure to information, in a similar fashion to infectious diseases (Richman & Jason, 2001). Recent findings show that although symptom reporting remained fairly constant over the past years, the incidence of CFS/ME and fibromyalgia has risen dramatically, which is more likely to reflect fashions in diagnostic labelling rather than true changes in incidence (Hamilton *et al.* 2005). This process of dissemination, engaging patients, their friends and family members, support groups, self-help literature, sensationalized media coverage and the clinical and research community, demonstrates the cultural shaping of illness and disease (Abbey & Garfinkel, 1991). It might be one answer for the intriguing observation that whereas fatigue states are universal, the CFS concept is largely confined to the English-speaking countries and northern Europe.

The road to diagnosis

Not all, indeed not many, patients fulfilling the criteria for CFS receive a formal diagnosis. As it appears, CFS is largely under-detected in the general population. The probability of receiving a formal diagnosis depends on individual factors such as access to health care, one's personal view of the illness, readiness to engage in a lengthy process of vigorous health-care seeking, the determination to find a diagnosis that matches one's symptoms, beliefs and aspirations, and on the attitude of the doctors that are consulted.

Many CFS patients, particularly in hospital settings, share a strong conviction that their symptoms are physical in nature. A plausible explanation is that biological illness attributions provide legitimacy, alleviate personal responsibility and protect against stigma (Horton-Salway, 2001), as opposed to psychosocial illness attributions. As a result, CFS patients will seek doctors who offer explanations in keeping with their own illness beliefs.

For many of these patients, it is not so much the need for a formal diagnosis that drives them, but the search for relief, belief and understanding, something most doctors fail to see (Reid *et al.* 1991). Finding a label that fits one's symptoms may bring that relief and legitimacy, especially if the label is a biomedical one, free from the stigma of psychiatric illness. But most importantly, the act of labelling is an intervention in itself that brings an end to the unbearable burden of uncertainty. A controversial diagnosis like CFS may not be first choice as a label, but it is better than nothing at all (Zavestoski *et al.* 2004).

The battlefield of medical practice

Although the diagnostic process of CFS seems straightforward and unambiguous, the nature of CFS often spirals bitter debates between doctors and patients (Sharpe, 1998).

Many doctors see the diagnosis of CFS as a self-fulfilling prophecy (Woodward *et al.* 1995), a medical uncertainty that might lead to worse outcomes. Without doubt, some doctors are

annoyed by the perception of a patient-initiated transgression into the sick role. Medical trainees (Jason *et al.* 2001) and qualified doctors (Steven *et al.* 2000) alike judge CFS primarily to be a psychological or psychiatric problem. Patients who present with a self-diagnosis of CFS are regarded as difficult and time-consuming. Such attitudes of hostility may, however, be confounded by doctors' frustrations of being unable to help these patients (Hartz *et al.* 2000; Salmon & Hall, 2003).

Consequently, many CFS patients encounter doubts, disbelief and rejection when consulting their physician, and feel the reality of their symptoms is denied. The search for diagnosis then turns into a contest over diagnosis. This battle may contribute to the course of illness: if you have to prove you are ill, you cannot get well (Hadler, 1996).

At best, these conflicts over the diagnosis of CFS will lead to negotiations between doctors and patients (Zavestoski *et al.* 2004), but many patients will retreat from their doctor's office and reach out to others for help (Stanley *et al.* 2002): doctors who are sympathetic to the cause of CFS, alternative therapists who offer explanations in keeping with their own views, and, if all else fails, the act of self-diagnosis.

Labelling CFS: the advantages

Most arguments in favour of labelling CFS highlight the empowering appeal of a diagnostic label that fits one's symptoms. The act of diagnosis is central to the experience of CFS. From this perspective, shared by many patients, receiving a CFS diagnosis is an intervention in itself, a breakthrough that brings an end to the burden of uncertainty and de-legitimization and that determines the course of action to follow. Diagnosis generates comfort, relief, acceptance, credibility and legitimacy and leads the way to treatment and social and economic benefits. Diagnosis leads the way to patient organizations that provide support and information, although this information may not be consistent with the evidence base. Diagnosis can provide a refuge that preserves self-esteem and protects from (or takes away) stigma and the feeling of guilt. Diagnosis offers a socially accepted reason for failure to cope, especially if all miseries can be pinned on that disease. The diagnosis of CFS brings meaning to the suffering, a cathartic voice, much like a religious experience. It brings understanding and acceptance from others as well, although it does not generate sympathy from everyone.

Labelling CFS: the disadvantages

Arguments against the act of diagnosis for the most part thrive on the mediating effects of pessimistic illness beliefs on the course of complaints. Diagnosis elicits the belief the patient has a serious disease, leading to symptom focusing that becomes self-validating and self-reinforcing and that renders worse outcomes, a self-fulfilling prophecy, especially if the label is a biomedical one like ME. Diagnosis leads to transgression into the sick role, the act of becoming a patient even if complaints do not call for it, the development of an illness identity and the experience of victimization. Diagnosis may send patients in the direction of support groups, with their overrepresentation of chronic sufferers and frequent anti-psychiatric attitudes, although we should acknowledge the distinction between *bona fide* patient organizations and radical Internet pressure groups that are waiting for the still elusive 'medical breakthrough', relying solely on alternative treatments in the meantime. The dangers of labelling have raised some voices to abandon diagnostic labels such as CFS altogether.

In sum, receiving a CFS diagnosis may contain a harmful message that triggers or validates perceptions of ill health and catastrophic outcomes. If this message takes root in a person suffering from fatigue, prompted by personal beliefs, comments by others or the hostile reception of a physician, it becomes a self-fulfilling prophecy that perpetuates and exacerbates symptoms, with comprehensive consequences.

To tell or not to tell?

When we review the pros and cons of labelling CFS, it is clear that there is no consensus leaning to a particular direction. It leaves us with the question: should we tell or not? Are the potential adverse effects of labelling someone as a CFS patient valid reasons to abolish the diagnosis, or is it dangerous not to give a formal diagnosis to those who meet the case definition?

There is no single approach that deals with this question, and we have to rely on common sense. We advise that doctors base the

diagnostic process on the stage of illness and on illness beliefs.

For fatigued patients in an *acute* or *early* phase, it may be more appropriate to postpone an official diagnosis of CFS because the label may stimulate chronicity, rather than a focus on possible solutions. A recent study suggested that brief advice on activity soon after the diagnosis of acute infectious mononucleosis was enough to reduce fatigue (Candy *et al.* 2003).

On the other hand, a formal diagnosis of CFS may be the appropriate intervention when fatigue complaints have stabilized over a longer period of time and the chances of recovery are diminishing. For fatigued patients running out of options in an *advanced* or *chronic* phase of illness, the pros of labelling may come into action, bringing relief, acceptance and the preservation of self-esteem to the experience of illness.

In either case, doctors should use positive strategies in the management of fatigued patients. As we have seen, there is a world of trust and constructive cooperation to be gained. We propose a general management strategy including the following elements:

- seek an active alliance with the patient;
- explore the meaning of suffering, complaints and predefined illness beliefs;
- acknowledge suffering, but discourage the sick role or maladaptive illness beliefs;
- provide accurate information but be restrictive with implicit prognoses that fuel illness beliefs;
- provide simple advice aimed at the necessity to balance rest and activity;
- empower the patient to take an active, responsible role in recovery, without inducing blame or guilt.

Sound evidence for the treatment of CFS is still poor. For patients seeking active treatment, cognitive-behavioural therapy (CBT) and graded exercise therapy (GET) are currently the best available options (Whiting *et al.* 2001). However, it should be kept in mind that evidence from randomized trials bears no guarantee for treatment success in routine practice. In fact, many CFS patients, in specialized treatment centres and the wider world, do not benefit from these interventions. When it comes to the management and treatment of CFS patients, there is still a lot to be learned.

Conclusions

Perhaps the essential ambiguity of CFS and the other contested diagnoses, with the contrast between normal appearance and far from normal feeling, and the lack of objective or medically accepted disease verification, continues to leave the sufferer stranded uncomfortably between illness and disease. Although we have focused on psychological, psychosocial and cultural factors only, we do not wish to deny there are physical complexities of CFS that exist beyond our present scope. We also acknowledge some people will argue that the only question worth asking about CFS is what is the cause, and that discussion about the meaning of diagnosis and its risks and benefits is at best meaningless and at worst an offensive distraction. Finally, it should be noted that our conclusions are primarily based on common sense, in the absence of a sound evidence base.

Ultimately, the balance of benefit and harm that comes from the act of diagnosis can only be established by a randomized trial, perhaps similar to the one performed by Thomas in general practice (Thomas, 1978), and recently repeated by Knipschild & Arntz (2005). Despite the presence of true equipoise, we feel that our modern ethical climate means such a trial is unlikely to be performed in the field of CFS.

The answer to the question of 'to label or not to label?' may eventually turn out to depend not on the label, but what that label implies. Unfortunately or not, CFS has gained a realm of its own in many people's lives, and there is no use in ignoring that. In the absence of definitive data, and in the expectation that such definitive data will never appear, our final judgement is that it is acceptable to make diagnoses such as CFS, provided that this is the beginning, and not the end, of the therapeutic encounter.

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Declaration of Interest

None.

Note

Supplementary information accompanies this paper on the Journal's website (http://journals.cambridge.org).

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