

Doctors and social epidemics: the problem of persistent unexplained physical symptoms, including chronic fatigue

AMONG general practitioners (GPs) opinion has been divided about the validity of chronic fatigue syndrome or myalgic encephalopathy (CFS/ME) as an illness.¹ Now, in a report to the Chief Medical Officer (CMO) an expert group has concluded that the condition is indeed a chronic illness meriting significant NHS resources, including the unre-served attention of the medical profession.² Widespread publicity was given to the CMO's enthusiastic reception of the report, which included the statement: 'This is a real disease affecting real people'.

Amid controversy,³ the approach adopted by the group became dominated by the perspective of sufferers and, predictably, led to the conclusion that the scale and, in some cases, the severity of the condition, establish its authenticity and dictate the need for NHS provision. While emphasis on the experience of sufferers is to be welcomed, evidence of this kind requires more than superficial analysis; it must be interpreted within a rigorous scientific framework such as that afforded by the methods of qualitative research.

Moreover, the group's recognition of CFS/ME as a distinct syndrome runs counter to trends in recent research.^{4,5} Chronic fatigue is one of a diverse group of physical symptoms which have long defied satisfactory explanation by the medical profession⁶ and which have been diagnosed in different ways according to the prevailing medical fashion; a century ago it would probably have been labelled 'neurasthenia'.⁷ As the CMO's group recognised, chronic fatigue seldom occurs in isolation.^{4,5,8} Systematic examination of the primary care records of a large number of patients with persistent unexplained physical symptoms reveals that they present with a diverse array of symptoms (including fatigue or its synonyms) which, on analysis, fail to cluster into discrete syndromes.⁹ Hence, it is likely that the 'reality' of discrete syndromes such as CFS/ME reflects bias in the referral and selection processes inherent in medical specialisation.⁴

The scale of the problem is therefore much wider than symptoms of chronic fatigue. In primary care, about 20% of patient-initiated consultations concern physical symptoms with no satisfactory pathological explanation.^{4,10} While for many patients these symptoms resolve spontaneously,^{11,12} in a minority they become persistent and remain unexplained following investigation and specialist referral. Patients with persistent unexplained physical symptoms (PUPS) believe themselves to be ill,¹³ experience disability comparable to that seen in chronic physical illness⁹ and usually, but not always, are depressed and/or anxious. Qualitative research reveals attributions seen in many other types of illness not of psychological origin¹³ and much unhappiness with the reactions of doctors to their symptoms, including the quality of explanations given.¹⁴ From this

situation — of illness beliefs and behaviour without demonstrable pathology — stem two general patterns of interaction between patients and doctors. First, to sustain an effective working relationship, patients and doctors opt to transact around an agreed symptom or set of symptoms and use this to reach expedient decisions about treatment and referral.⁹ Second, no such accommodation is reached and patients seek support and advice from fellow sufferers via the agency of syndrome-specific support groups and treatment from complementary practitioners.² Thus, in contrast to the trend in recent research to view PUPS as a generic problem, both clinical practice and the activities of pressure groups are tending to perpetuate discrete syndromes such as CFS/ME.

This divergence is of more than academic interest: while few would question the need to help patients with PUPS, the issue of which intervention is likely to be beneficial has been clouded by research in secondary care conducted among highly selected sub-groups of referred patients. Studies suggesting that physical exercise¹⁵ or cognitive psychotherapy¹⁶ are beneficial can be criticised on these grounds.² The prevailing view in UK primary care has been that somatisation of mental illness is the basic problem^{17,18} despite evidence that depression and anxiety are not ubiquitous in PUPS and are just as likely to be secondary as primary.^{9,19} The view that anxiety and depression are epiphenomena is reinforced by recent research which demonstrates that the development of multiple physical symptoms is not an effective defence against acknowledgement of psychiatric disorder.²⁰ Alternative approaches to care which focus on changing the way patients and doctors communicate about the illness and, in particular, incorporate and modify patients' beliefs within an agreed management strategy, are gaining ground.²¹ In the day-to-day management of patients with PUPS, qualitative research indicates that GPs should neither deny nor acquiesce with patients' interpretations of their symptoms. In this way they avoid the risks either of being perceived to reject the patient or of unintentionally colluding with the patient. Rather, they should try to fashion explanations of the illness which empower patients to take a more active role in their own recovery.¹⁴

Are we any closer to a satisfactory account of the pathogenesis of PUPS (and therefore of CFS/ME) than we were in 1996, when the Royal Colleges of Physicians, Psychiatrists, and General Practitioners comprehensively reviewed the evidence?²² There is growing recognition that the terms 'medically unexplained' and 'pathogenesis' each reflect limitations in the profession's explanatory models of illness behaviour. Thus, attempts by the CMO's group to reach agreement on an intellectually coherent pathogenesis for CFS/ME foundered on sterile dualistic reasoning according to which genuine physical symptoms can only result

from a disease process, be it biomedical or psychological, *inside* the patient.³ In contrast, a number of authors^{6,23} have pointed to the primacy of cultural and social factors in creating ill-defined syndromes, suggesting that they are akin to other types of 'social epidemic'.²⁴ In particular, we inhabit a society in which medical information has become all-pervasive. The fascination of the media with such information raises general awareness of the potential significance of commonplace symptoms without providing any countervailing sense of perspective. Some individuals, perhaps rendered vulnerable by a range of social and inter-personal setbacks, may translate physiological manifestations of unhappiness (or even of normal functioning) into symptoms of illness, with the gains involved in adopting victim status. Consumerism in health care, including the activities of pressure groups, creates a climate in which the subjective is less easily dismissed by doctors, despite negative investigations and an array of symptoms that is incoherent in pathological terms. Thus the key influence on the perpetuation of unexplained symptoms appears to be the medical profession itself: Barsky²⁵ has identified a number of iatrogenic mechanisms and recently we have reported evidence that unintentional collusion between GPs and their patients is shaping, reinforcing, and legitimising pseudo-syndromes.⁹

The evidence indicates that doctors, both individually and as a profession, need to make a clear distinction between engagement with PUPS and medicalisation of the problem: between encouraging and empowering patients to assume greater responsibility for their recovery and acquiescence in the reality of the 'illness'. The fundamental criticism of the CMO's group is that by adopting an approach that, in effect, allowed consumerism in health care to define an illness, it surrendered a role reserved for the profession's established scientific methods. Its recommendations, therefore, need to be interpreted with caution. High-level recognition that PUPS are a significant problem for patients and doctors (particularly for the generalist charged with long-term care) is to be welcomed. More research, especially among primary care patients into the transition from short-term to persistent unexplained symptoms, is clearly justified. However, while addressing evident demand, the uncritical diversion of NHS resources, and particularly medical manpower, into CFS/ME care will not diminish the problem for patients or doctors. For, unless the medical profession clearly understands its role in the management of illness beliefs and behaviour in the absence of demonstrable pathology, it risks becoming both an intellectual casualty and a potent vector of this and other social epidemics.

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