Chronic fatigue syndrome:

is the biopsychosocial model responsible for patient dissatisfaction and harm?

In 1977 George Engel wrote about the need for an 'integrated approach' in medicine that moved the focus beyond biological mechanisms of disease to include all pertinent aspects of illness presentation, setting out a 'biopsychosocial model'.[1] Around the same time, McEvedy and Beard asserted that the disease '*benign myalgic encephalomyelitis*', described by Ramsay at the Royal Free Hospital, London, was nothing more than a case of 'mass hysteria'.[2] In the 1980s, doctors combined theories of neurasthenia, hysteria, and somatoform illness, to reconstitute ME as '*chronic fatigue syndrome*'. Psychiatrists argued that CFS was best understood using a biopsychosocial (BPS) framework, being perhaps triggered by viral illness (biology), but maintained by certain personality traits (psychology) and social conditions (sociology).[3] Although the BPS model holds much utility in understanding 'illness' in a wider context, many sufferers of CFS reject the notion that their illness is psychologically or socially derived. Significant numbers of patients report difficult interactions with doctors that leave them feeling dissatisfied, disbelieved, and distressed. In this article, we question whether or not the BPS model generates 'harms' for CFS patients, and we ask if other, alternative approaches might be more preferable to both patients and GPs.

THE POTENTIAL FOR IATROGENESIS

GPs are increasingly encouraged to apply biopsychosocial principles in the clinical assessment of patients with medically unexplained symptoms, particularly CFS.[3,4] There is a general argument put forward in the BPS literature that patients with CFS have higher rates of depression and anxiety, are combative, and seek unnecessary investigations in an effort to maintain sick role status and avail of social benefits.[3] GPs are encouraged to challenge or reframe unexplained physical symptoms and to focus attention on issues such as potential somatisation.[3] Patients calling for enhanced medical investigation are to be judged as seeking unnecessary tests and perhaps unnecessarily availing of scarce resources.[3] Raine and colleagues found that GPs often negatively stereotype patients with CFS as 'problematic' or 'hypochondriacs', with a view that these patients are not suffering from clear pathological illness, but are patients with complex psychological and social problems.[5] However, is this narrative correct? There is increasing scientific evidence that confirms a range of physiological abnormalities in CFS. In 2011, a panel of experts published an International Consensus Criteria for CFS that promoted a neuro-immune model, rather than a psychogenic model, and in 2015 the US Institute of Medicine (IOM) suggested renaming CFS 'Systemic Exertion Intolerance Disease' (SEID), taking note of the multiple physical complaints patients endure.[6] In contrast, GPs in the UK and elsewhere are encouraged to apply a biopsychosocial approach to CFS, including referring patients for psychological assessment and treatment within specialist centres.[3,4] The BPS framework for CFS proposes that patients' abnormal psychopathology (essentially somatisation) may be treated with cognitive behavioural therapy (CBT) to alter patients' 'illness beliefs', and graded exercise therapy (GET) to change 'fear avoidance behaviours'.[3] However, the 2015 IOM report stated that the symptoms most CFS patients present with — fatigue, pain, cognitive disturbances, or orthostatic intolerance — are unlikely to be 'dysfunctional illness beliefs'.[6]

The biopsychosocial framework is contested by CFS patient advocacy groups, with claims that the BPS model is biased to the 'psychological', including reliance on CBT and GET. The evidence for the success of psychotherapies in CFS treatment is mixed. A 2011 psychiatry-led randomised control trial of CBT and GET for CFS reported a 22% improvement in subjective outcomes (wellbeing). However, this was not mirrored by objective measures of improvement (physical functioning), and at follow-up return to employment did not increase, healthcare usage remained the same, and patients reported a similar level of social welfare benefits.[7] Although CBT and GET may help some patients, these treatments are not universally welcomed by all patients with CFS and there is some evidence that graded exercise may exacerbate symptoms.[8] In a 2010 ME Association survey of 4217 members, 57% of responders reported graded exercise therapy as being unacceptable as a treatment.[9] Other patient surveys report similar findings of patient dissatisfaction and distress following engagement with CBT or GET.[10] In addition, a study of referrals to CFS clinics found that 37% were rejected as inappropriate and 61% had a likely alternative diagnosis.[11] For patients assessed in-clinic, 43% had alternative medical/psychiatric diagnoses, commonly sleep disorders or depressive illness.[11] In a separate study, two-thirds of patients with CFS referred to CFS clinics reported being dissatisfied with the quality of medical care they received.[12] Dissatisfaction was associated with delays and disputes over diagnosis, rejection of a psychiatric diagnosis, as well as doctors being dismissive, sceptical, and lacking in knowledge about the condition.[12]

Within the BPS framework, GPs may be inappropriately encouraged to view physical symptoms, such as pain, as being 'somatised',[3] rather than complaints that require intervention, such as analgesia or referral to a pain clinic. If CFS patients perceive that GPs do not view their symptoms as 'legitimate' and 'physical' (that is, aberrations), patients may withdraw from seeking medical support. There is some concern that, if a patient with CFS rejects the BPS rationale for the illness and/or interventions of CBT/GET, this may be viewed negatively by a GP.[5] In a patient advocacy group survey, 22% of CFS sufferers reported that they received no medical care, while the average rating given by those who did receive care was just 24%.[9] Across a number of studies, sufferers of CFS reported doctors being hostile and dismissive, leaving many patients feeling

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'stigmatised' and 'marginalised'.[5,6,9–12] Low levels of satisfaction around provision of care is a concern, as CFS is often a debilitating condition that greatly impacts on patients' quality of life, leaving many vulnerable to secondary depression and suicide.[6]

CONCLUSION: INVOLVING PATIENTS AND EMPOWERING GPS

Many CFS patients report that they wish to be cared for by GPs in primary care, rather than psychiatrists in specialist centres. CFS patients ranked the professionals they want to manage their condition, putting GPs as first choice (1502 votes), with psychiatrists last choice (15 votes).[10] However, in a survey of attitudes to CFS among English GPs, Bowen and colleagues found that many GPs lack confidence in making a diagnosis (48%) or in treating patients (41%).[13] Scepticism and a lack of awareness and training among GPs concerning CFS may well explain some of the patient dissatisfaction highlighted in patient surveys, as well as explain delays and error in diagnosis. However, it is also arguable that the biopsychosocial approach of challenging the nature of the illness, and seeking to intervene with psychotherapy to challenge patients' illness beliefs may also play a part in generating distress for patients with CFS. In order to minimise iatrogenesis, GPs require better training in how to diagnose CFS and communicate with patients with CFS; GPs should not seek to impose a biopsychosocial model of illness on a patient. Models of illness should not supplant the 'lived experience of illness' or subjugate the expert status of the patient as 'witness to their condition'. Nassir Ghaemi, critical of the biopsychosocial model, suggests doctors should consider alternative clinical approaches, such as Karl Jaspers' 'method-based' or William Olsen's 'medical humanist' model'.[14] Such models might be used by GPs to:

- inform patients of the absence of known aetiology in CFS (rather than speculating around psychogenic causes);
- inform patients that there are explanations for some CFS symptoms (for example, the IOM report of biomedical evidence);
- offer patients treatments such as CBT, but inform patients that these therapies do not work for all (rather than suggesting the patient controls outcomes);
- offer alternative interventions and support, such as counselling and community care (rather than just referral to CFS clinics); and
- accept the legitimacy of the patient account (rather than seeking to challenge patients' illness beliefs).

Such differences of approach may seem subtle, but arguably represent a more pragmatic approach, which we recommend for general practice. It is probable that harm could be minimised by adopting a more concordant model that includes patients' preferences in treatment and management.

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Provenance
Freely submitted; externally peer reviewed.

Competing interests
The authors have declared no competing interests.

DOI: 10.3399/bjgp16X686473

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