Fibromyalgia: why such controversy?

The title of my 1987 article, 'Fibromyalgia syndrome: an emerging but controversial condition,' has proved prophetic.1 Fibromyalgia has indeed emerged, at least in much of the world, as a common and recognisable cause of chronic, diffuse musculoskeletal pain. Fibromyalgia has been found to be present in 2–5% of the population, in 5–20% of medical clinics,3 and is recognised as the second most common disorder seen in American rheumatology practice.5 Nevertheless, controversy persists regarding criteria for diagnosis, potential pathophysiology, and treatment. Some prominent rheumatologists, particularly in the United Kingdom, question the very existence of fibromyalgia. A review of these major controversial points should provide some focus on where we are today and where we are headed in understanding and treating fibromyalgia and related disorders.

Is fibromyalgia a discrete disorder that can be formally diagnosed?

Fibromyalgia is a recognisable syndrome characterised by chronic, diffuse pain, an absence of inflammatory or structural musculoskeletal abnormalities and a constellation of symptoms that include fatigue, sleep disturbances, and mood disturbances. Physical examination and laboratory testing are unrevealing, except for the presence of pain on modest palpation of characteristic soft tissue locations, termed tender points. Critics of the concept of fibromyalgia as a specific condition note the absence of any known physical or psychological pathology and the recent observation that tender points reflect a state of generalised hyperalgesia rather than focal pathology. However, the absence of tissue pathology does not preclude the presence of a recognisable illness, such as in migraine, irritable bowel syndrome, reflex sympathetic dystrophy, and most forms of regional pain disorders. When defining any illness lacking 'objective' pathology, it is important that the symptoms and signs of the illness should be characterised and classified, and the uniformity of those features evaluated in populations suspected of having the condition and populations suspected of not having the disorder. Such studies have been undertaken in fibromyalgia, the most extensive resulting in the 1990 American College of Rheumatology classification criteria (table).4 This and other studies have demonstrated that: (a) fibromyalgia can be differentiated from other rheumatic diseases, with an accuracy of 85%; (b) fibromyalgia may present independently of any other medical disorder but is also often associated with other chronic rheumatic diseases, including rheumatoid arthritis, systemic lupus erythematosus, and osteoarthritis, or associated with other poorly understood syndromes, including depression, migraine, irritable bowel syndrome, and chronic fatigue syndrome.

Critics of the diagnostic criteria question the validity of a circular argument in which the gold standard of diagnosis is based on the very acceptance of the notion that fibromyalgia is a specific disorder.5 However, expert consensus opinion forms the gold standard for any illness that lacks definitive laboratory or pathological findings. Although the tender point examination may reflect abnormal central pain perception rather than abnormal muscle, the diagnostic utility of the examination itself has been demonstrated by several investigations.4 Recognition of the homogeneity of fibromyalgia has given investigators the opportunity to share observations and develop novel paradigms for understanding chronic musculoskeletal pain. Such research has found no evidence for a primary pathological role of muscle in fibromyalgia.8 Investigators are now focusing on the interactions of abnormal peripheral and central pain mechanisms, in addition to the complicated interactions of sleep, mood disturbances and pain. Preliminary studies of neurohormones, growth hormone, and the hypothalamic-pituitary-adrenal axis have generated exciting new hypotheses suggesting altered stress regulation impacting the central nervous system in fibromyalgia.7,9

Do diagnosis and treatment improve outcome?

The opponents of the concept of fibromyalgia consider it a 'non-disease' and suggest that the fibromyalgia 'label' is likely to create a population of 'worried well', with dire sociological and psychological consequences.10 The Australian experience with the diagnosis of repetitive strain injury warns us of the possibility of such negative disease labelling.11 My experience has been that the label of fibromyalgia provides a structure for patient understanding and a model for treatment (figure). Most patients with fibromyalgia have been shuttled back and forth from numerous physicians, and have undergone numerous costly and sometimes dangerous tests and ineffective treatments before the diagnosis; the average duration of symptoms before the diagnosis of fibromyalgia is five years. Once the diagnosis is established, fear of a degenerative disease ends and patient frustration and anger can be channelled into a programme of coping and rehabilitation.

Of course, simply pronouncing that the patient has a diagnosis is ineffective unless a detailed explanation about the condition, its treatment, and prognosis ensues. Patients need to understand that there is no progressive muscle
pathology and that avoidance behaviour and physical inactivity is counterproductive in any chronic soft tissue pain disorder, whether idiopathic low back pain or fibromyalgia (figure). Careful discussion of the interplay of soma and psyche should be based on fibromyalgia research in sleep, mood, and potential neurohormonal interactions. The chronicity of the illness should be addressed, as most studies demonstrate that fibromyalgia is a chronic disorder with few remissions and persistent pain and fatigue. However, most of such longitudinal studies have followed tertiary referral rheumatology patients with coexistent significant psychopathology. In contrast, a recent community based study reported that after two years of treatment, 47% of fibromyalgia patients no longer fulfilled diagnostic criteria and 24% were in remission.

Tricyclic medications, such as amitriptyline and cyclobenzaprine, and certain other central nervous system active medications have been more effective than non-steroidal anti-inflammatory medications or placebo in short term controlled clinical trials. However, major clinical improvement has occurred in only about 25% of patients, and appears to lessen over time. Non-medical treatments that have shown some efficacy include cardiovascular fitness exercise, regional sympathetic blockade, electroacupuncture, hypnotherapy, electromyography-biofeedback, and cognitive behavioural therapy, including stress reduction, relaxation response training. Multi-disciplinary treatment programmes which focus on education, teach the importance of self help, and utilise a team of mental health and physical medicine and rehabilitation specialists, may be cost effective in fibromyalgia patients with the greatest levels of pain and disability.

Without such educational approaches and comprehensive pain management, fibromyalgia can indeed be a disabling disorder. In many countries, fibromyalgia is a common cause of being categorised as unfit for work and an increasing cause of litigation and compensation. However, this is not a consequence of the fibromyalgia label but rather a consequence of the focus by society on entitlement and the medical professions’ inability to deal effectively with chronic physical and psychological pain.

**Current and future recommendations**

The controversy over fibromyalgia has been fuelled by the increasing recognition of this clinical disorder. Opponents of the fibromyalgia concept suggest that fibromyalgia terminology and diagnostic criteria are flawed. Indeed, we do not know how to classify patients who hurt all over, patients who do not have at least 11 of the 18 tender points, those with secondary gain from their illness, and those with coexistent major mood disturbances. Yet, we at least have a common illness in mind when sharing observations and research studies from around the world. Opponents of the fibromyalgia concept argue that, as it is a non-disease, we are legitimising patients’ sickness behaviour by providing a disease label. I would argue that unhappiness in work, psychosocial issues, and inherent personality traits, not disease labels and diagnostic terms, promote disability. Furthermore, many of the patients with what we now call fibromyalgia have suffered through numerous medical and surgical misdiagnoses and ineffective treatments, driving them further to despair and depression. The label of fibromyalgia, put in its proper perspective, provides a health care professional with the basis to recommend activity, rather than inactivity, work modification, rather than work termination, and coping rather than catastrophising.

In conclusion, the clinical syndrome that we now recognise as fibromyalgia has been with us for centuries and is here to stay. In common with other similar poorly understood syndromes, including migraine, irritable bowel, and depression, failure of the patient to fulfil Koch’s postulates and the absence of objective physical and laboratory abnormalities does not mean that the patient is not ill or in distress. We must accept that some patients’ physical and emotional pain may be ‘disabling.’ In a non-judgmental fashion we must steer them away from sickness behaviour. Rather than worrying about the best label or set of diagnostic criteria for fibromyalgia and related syndromes, we need to focus on the complicated psychosocial and biological factors that distinguish individuals who cope very well with these symptoms and move ahead with their lives, in contrast to those who are mired in the depths of chronic pain.

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