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Fibromyalgia: a challenge for modern medicine

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Introduction

The article by Ehrlich [1] rightly points to the hazards of the diagnostic concept of fibromyalgia (FM). However, the author appears to be highly biased by a medicolegal perspective. As a liaison psychiatrist with a main interest in FM, chronic fatigue syndrome (CFS) and other 'functional somatic syndromes' [2,3], I disagree on several points with Ehrlich's comments. In what follows I will try to demonstrate that FM, viewed from a broader clinical perspective, is a kind of 'ill health' that constitutes a formidable challenge for modern medicine. My commentary will be organised around six topics: concepts and terminology; diagnostic assessment; labeling; aetiology; pathophysiology; and assessment of disability. I will conclude with some considerations about the task of modern medicine.

A virtual disease? Perhaps. A real illness? Definitely!

The term 'disease' usually refers to a well-defined medical condition, based on a specific pathological process [4]. FM – a syndrome consisting of widespread pain, tenderness, and non-specific symptoms such as sleep problems, fatigue and effort intolerance – cannot be considered a 'disease', because the above conditions are not fulfilled. Not only is there much criticism regarding the definition [5–7] and uncertainty about the aetio-pathogenesis [8], but it has also been argued that FM is not a discrete entity but the end state of a spectrum of pain and tenderness [9,10]. Others have claimed that FM

patients should be divided into subgroups, for example those with an idiopathic symptom onset, and those with a post-traumatic onset [11–13]. On the other hand, a strong plea has been made for classing all kinds of functional somatic syndromes (FM, CFS, irritable bowel syndrome etc.) together, as they clearly overlap and may even be considered 'an artefact of medical specialisation' [2,14].

In contrast, the term 'illness' connotes a subjective state of physical, psychological and social suffering which can only be understood and defined within the individual's experience [4,15]. Many studies have documented the suffering of patients with persistent pain, involving not only physical misery, but also emotional distress associated with psychological losses, an unpredictable outcome, and a frequent lack of social recognition [16].

Thus, although patients with chronic widespread musculoskeletal pain and fatigue may not have a discrete disease [1], they undeniably suffer from a very real illness [17,18]. But how should this kind of ill health be diagnosed and labelled?

Tender points or tender patients...

In 1990 the American College of Rheumatology recommended tender point measurement as the only reliable diagnostic tool for FM [19]. Although originally intended for classification and research purposes, 'tender points' have rapidly become the diagnostic hallmark of FM in the clinic. However, basing a diagnosis on 'the doctor's thumb' takes neither the complexities of the patient's illness experience into account, nor the cognitive-perceptual, emotional, and sociocultural biases affecting symptom reporting [15]. Moreover, during the last decade the specificity and clinical usefulness of the tender point criterion has been increasingly called into question [20,21].

At present, it is assumed that the core symptoms of FM (widespread pain, mechanical allodynia and

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hyperalgesia) are based on a hypersensitivity of central pain mechanisms, whereas tender points have been considered 'a marker of distress or somatisation' [22].

Interestingly, some years ago we published an article in this journal, discussing the possible aetiological role of psychopathology in FM, and the importance of a thorough exploration of previous and current life stresses in these patients [23]. Others, however, have claimed that psychopathology might primarily be a reaction to the illness [24], or not linked to the illness itself but to the patients' healthcare seeking [25]. Meanwhile, several studies (also in the community) have shown that FM is in most cases intrinsically related to pre-existing or concurrent psychosocial or psychiatric problems [26,27]. In our experience, the onset of FM (and CFS) is often associated with the chronic stress of an overactive lifestyle, pathological perfectionism, or self-sacrificing care-giving behaviour [28,29]. Moreover, a substantial subgroup of FM patients has been victim of severe adverse experiences, such as emotional neglect, physical maltreatment, or sexual abuse during childhood and/or adulthood [30,31]. It appears that many of these patients have long tried to keep their head above water, but eventually end up as 'exhausted fighters' [18].

The lesson to be learned from the above is that the diagnosis of FM (and other functional somatic syndromes) should not be limited to the assessment of clinical features, but essentially requires careful listening to the patient [32]. That such listening is more the exception than the rule in contemporary medicine is clearly illustrated by a clinical case conference on a CFS patient, published in an authoritative medical journal [33].

Labeling may be good for your health

The 'FM' label for these patients should not necessarily be 'iatrogenic', as Ehrlich [1] and others [7,34] contend. For example, in a recent study it was found that this label did not negatively affect the long-term outcome of patients with chronic widespread pain [35]. Evidently, the purpose of the 'FM' label is not to 'reify' the patient's distress into a disease construct, but to integrate symptoms and functional limitations into a descriptive term that makes communication about the illness easier [4,36].

A diagnostic label further reassures the patients that their condition is known by the doctor, that there might be an explanation for it, and that their symptoms and suffering are real and legitimate. This may lessen anxiety and worrying, restore a sense of predictability and control, prevent further 'doctor shopping', and stop the relentless search for a biomedical cause [4,36].

When asked for the underlying cause of 'FM', the physician should present only tentative explanations, such as 'your pain system might have become hypersensitive' [18]. The patient should further be informed that no causal treatment is available, but amelioration

will certainly be possible by symptomatic measures and – above all – by learning to cope with the illness.

Thus, giving a name to the illness and using it constructively will not 'foster a life of somatising' [1], but rather open a perspective on pragmatic treatment, aimed at optimising physical and mental functioning and quality of life, by promoting active coping, self-efficacy and long-term self-care [37,38].

Overcoming aetiological simplicity

In medicine, aetiology is all too often explained in simple monocausal terms, whereby 'organic' and 'psychogenic' causes are dichotomised [39]. Within a broader biopsychosocial perspective, however, the aetiology – particularly of functional somatic syndromes – must be considered multifactorial (implying a complex interplay of physical and psychosocial factors) as well as multidimensional (implying predisposing, precipitating and reinforcing/maintaining factors) [40,41].

As mentioned above, the history of FM patients often reveals longstanding psychosocial vulnerabilities, as well as precipitating physical overburden and emotional distress, which may interact with a genetic predisposition. Furthermore, symptoms and disability may be perpetuated by somatic hypervigilance (giving rise to symptom amplification); maladaptive illness beliefs; activity avoidance (leading to physical deconditioning and disuse); persistent sleep disturbances; anxiety and depression, related to the stress of the illness or ongoing familial or professional problems; and operant conditioning of illness behaviour (e.g. because of protracted compensation/litigation disputes).

This broad view should replace common medicolegal dilemmas, for example whether FM symptoms are caused by a prior whiplash injury, or related to a pre-existing psychiatric condition [42]. It seems more plausible that a physical trauma – particularly when associated with chronic emotional distress, poor coping, and lack of support – may in vulnerable individuals facilitate the development of an abnormal and persistent pain response, which in turn may impede normal healing and recovery [18].

Intensive research is now being carried out to unravel the exact nature of pathophysiological processes playing a role in the initiation and chronification of pain and other FM symptoms – see below.

Somatisation is not 'all in the head'

When the patient's pain and other symptoms cannot be explained within the biomedical model, doctors often refer to 'somatisation' – which patients generally interpret as 'psychogenic' or even imaginary. However, there is now ample evidence that somatisation should be

rethought of as a process involving not only psychological or psychophysiological, but also neurobiological mechanisms [43,44].

It has been consistently found that the hypothalamic–pituitary–adrenal (HPA) axis may be hyporeactive in various functional somatic syndromes, probably resulting from a lack of central drive [45–47]. This seems to reflect a downregulation of the stress response system after a prolonged period of functioning ‘in overdrive’ – which is consistent with the patients’ life histories [32]. Interestingly, very similar findings have been reported in post-traumatic stress syndrome [48], which not rarely co-occurs with FM [49]. These neuroendocrine dysregulations may be associated with immune disturbances, such as an abnormal production of proinflammatory cytokines, leading to a typical ‘sickness response’ and possibly being responsible for the lower pain threshold, postexertion malaise and concentration difficulties in FM patients [50].

Abnormal pain sensitivity may also be fostered by autonomous nervous dysfunction, inhibition of descending pain mechanisms, peripheral and central neuronal sensitisation, and an increase of pro-nociceptive neuromodulators (such as substance P and nerve growth factor) [45–47]. Recent evidence from neuroimaging studies seems to confirm the involvement of dysfunctional brain processes [51].

Although the exact nature of the above disturbances is unknown, it could be expected that the new and integrative sciences of psychoneuroendocrinology and psychoneuroimmunology will ‘bridge’ the cartesian gap between (neuro)biological and psychological factors in FM, and further elucidate the impact of ‘the story on the body’ [32,52,53].

Assessing disability in FM

People with FM are not only ill, their symptoms may strongly interfere with daily functioning and lead to marked life disruption [54]. Many authors have written about the thorny problem of disability determination in FM [55,56], and this has given rise to heated medicolegal discussions and an avalanche of critical editorials (see, for example, [57]).

Certainly, assessing disability in patients with functional somatic syndromes is a difficult task, containing many pitfalls [58]. For example, ‘objective assessment’ is in the medicolegal setting often misconceived as ‘verification by measurement’. Strictly speaking, however, the term ‘objective’ refers to the criteria of validity and reliability, i.e. aims at excluding personal bias as much as possible. Nobody will deny that disability in psychiatric disorders can be objectively evaluated, without any measuring, by carefully listening to the patient’s self-report. Why should functional somatic syndromes such as FM be treated differently from a medicolegal point of view?

Thus, questioning in detail the patient’s physical and mental functioning – while keeping an eye on the

internal logic and consistency of the answers – and at the same time evaluating the interference of psychosocial aspects (such as the patient’s emotional state and the availability of familial support) may in most cases allow one to ‘objectively’ determine functional capacities and limitations [18]. Psychometric testing [59], work-simulating tasks [55], and gathering information from significant others can be of additional value, but should always be interpreted within the patient’s personal narrative.

Evidently, work disability assessors are also obliged to prevent possible misuse of the social security system. They ought, for example, to be aware of the increasing impact of FM self-help organisations, pressure groups and the modern media (such as the internet) on the patients’ symptom presentation [1,60,61]. However, this should not lead to paranoid-like prejudices, whereby every FM patient is suspected to be a potential malingerer who should even be watched by a ‘candid camera’ [62,63].

Finally, work disability in FM patients is a social problem as well. To be able to remain at work depends not only on the patient’s functional limitations, but also on the willingness of employers to adjust work environments and work tasks, and to provide individualised solutions [64]. From a broader societal perspective, the time has come to investigate why stress-related illnesses seem to increase in all western countries, and to discuss how society could best handle the growing numbers of work disability and compensation claims of those who succumb [18].

Modern medicine and ill health

Should medicine only focus on symptoms and syndromes that have reached a full ‘disease’ status? Should doctors close their eyes to human suffering that cannot be proved by hard evidence? Should these kinds of ‘illness-without-disease’ be disqualified as ‘non-diseases’, i.e. not deserving medical attention [65,66]?

To answer these questions, consider a curious paradox that has developed during the last few decades. Although medicine has never been more evidence based than today, thousands of patients follow the hazardous paths of alternative or complementary medicine [67]. Could it be that conventional medicine, by focusing excessively on its technical and scientific power, oversimplifies the complex and interpersonal nature of clinical care, and by so doing loses the art and humanity of its practice [16,68–70]?

In this sense, FM challenges modern medicine and its practitioners. FM – and other kinds of ill health – invites us to accept *all* suffering, even when it is not based on ‘objective’ impairment and thus not ‘falsifiable’ [1]. The syndrome reminds us that a trustful therapeutic alliance, an empathic and non-judgemental relationship style, and a commitment to continuing care can be extremely powerful therapeutic tools. It makes us realise that we

should better value non-specific treatment effects, which nowadays seem to be the privilege of non-conventional medicine.

Ehrlich is right to state that 'medicine is ill-prepared to deal with FM patients' social problems and adjustments' [1]. Much work remains to be done to increase doctors' knowledge about the psychosocial aspects of medicine, improve their communication skills, and organise adequate collaboration with mental health professionals [3,71,72], but in any case, neglecting the subjective in clinical medicine will lead to an impoverishment of the role of clinicians, and drive many patients into the doubtful arms of alternative healers.

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