

Pain is real; fibromyalgia isn't.

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*The Journal of Rheumatology* is a monthly international serial edited by Earl D. Silverman featuring research articles on clinical subjects from scientists working in rheumatology and related fields.

## Fibromyalgia — Real or Imagined?

In this issue of *The Journal* we highlight 3 different editorial views of fibromyalgia (FM) based on the results of a study in an Amish community in rural Southwestern Ontario<sup>1</sup>. The study was inspired by the possibility that FM could be symptomatic of a breakdown in societal values expressed by patients seeking disability compensation benefits<sup>2</sup>.

Dr. Ehrlich, in his editorial, expresses the view that patients with chronic widespread musculoskeletal pain who encounter a rheumatologist and are labeled with the diagnosis of FM are poorly served<sup>3</sup>. In his opinion they become candidates for victimization by the “remunerative industry” of advocacy and medicolegal groups eager to certify them with “a hopeless prognosis.” As such, he sees FM as an untenable diagnosis because “no one has FM until it is diagnosed.” He calls for abandonment of the concept of FM because for patients, “pain may be real, but FM isn’t.”

In Dr. Hadler’s view, persons who “have exhausted their wherewithal to cope” and enter the medical stream may become victims of the iatrogenic medical construct of FM<sup>4</sup>. The ineffective “circular treatment acts” that they subsequently receive only reinforce illness behaviors. For this reason, he too would dismantle the construct of FM and focus instead on the mind-body psychosocial confounders of this unexplained condition.

In recent years I have also observed that many physicians express frustration directed not only at the FM construct, but also at the patient. This hostility seems related to the fact that patients with FM display very much more psychological distress than other patients. All this is further compounded by the lack of effective treatment for it and the fact that many patients have a record of adversarial interactions within the healthcare system<sup>5</sup>. It is not so surprising that some rheumatologists will not see patients that are referred to them for FM and others will only see the patient for a one-time assessment to exclude other conditions, but not provide ongoing care<sup>6</sup>.

In his editorial, Dr. Wolfe examines why the American College of Rheumatology (ACR) criteria for the classification of FM have not met expectations<sup>7</sup>. For some, they only seemed to have served as a flashpoint to ignite and inflame controversy. In his analysis, Wolfe sees tender points as a distraction from the central psychosocial symptoms of

patient distress. He worries that the ACR classification criteria are based on such an extreme degree of severity that they imply disability<sup>8</sup>. Moreover, in a comparison of patients with rheumatoid arthritis and FM he shows a bimodal distribution of FM features, in keeping with the view that FM-like illness can be identified in both conditions without a requirement for tender points. Thus, Wolfe presents original data to support his contention that ACR criteria should not be used in the clinic or in medical reports.

Finally, no matter where we put FM in our diagnostic lexicon, rheumatologists who care for patients continue to see chronic musculoskeletal pain unexplained by an identifiable organic disease<sup>4</sup>. If what some of us call FM is ever to be better managed, more research is required to identify the many factors that seem to cause and perpetuate this vexing medical problem<sup>5,9</sup>.

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## Pain Is Real; Fibromyalgia Isn't

When one has tuberculosis, one has tuberculosis, whether or not it is diagnosed. The same is true for cancer, rheumatoid arthritis, hookworm infestation — really, of the gamut of diseases. But not for fibromyalgia (FM). No one has FM until it is diagnosed.

Chronic pain? Surely. The proportion of people who have chronic pain tends to be similar in all climes and cultures. But chronic pain isn't FM. The London, Canada, group has found a proportion of Amish who have chronic pain<sup>1</sup>. They were never diagnosed as having FM until these investigators labeled them. In the context of the Amish culture, the diagnosis is meaningless.

Even when psychological factors, social and vocational dissatisfaction, and urban stresses are taken into account, chronic pain remains chronic pain, without physical or organic signs or specific laboratory or imaging abnormalities. Until a doctor diagnoses FM. Then support and advocacy groups aggravate the problem, disability is certified, a hopeless prognosis is offered; and in sophisticated societies, some antecedent event is blamed and the tort lawyers and their experts for hire spring into action. Thus have we turned a common symptom into a remunerative industry.

Everybody has pain sometimes, and even chronic pain during a lifetime. In Western cities, FM tends to be diagnosed when no other reason is found for the pain. The same pains in rural areas or developing countries go unmarked, and people get on with their lives. But not in Europe or North America. The illogic of the "I am the evidence" cry suggests innuendo and an ignorance of science and logic. The Austrian sociologist Ferdinand Toennies in another context identified 2 major social distinctions: *Gemeinschaft*, or community, for the nonurban population, and *Gesellschaft*, or society, for those in urban environments<sup>2</sup>. These distinctions apply well to the FM conundrum.

In rural areas, chronic complainers aren't well tolerated. In cities, one can round a corner and become anonymous. Chronic pain becomes involved in a lifestyle mix, and all manner of associated symptoms or nonsymptoms become

prominent when the individual focuses on herself and her discomfort (and it is mostly women who fall into this category). There are no objective findings and not even one acceptable definition. If one consults the Wallaces' book<sup>3</sup>, written for the public, anything goes.

The 1990 classification criteria were meant for grouping cases for reporting purposes<sup>4</sup>. Unfortunately, the FM proponents have often used these as diagnostic criteria, and then added other irrelevant common manifestations, mostly self-reported and unverifiable. They have also reported purported laboratory or other data that are neither specific nor sensitive and are shared with other chronic pain sufferers not diagnosed as having FM, and even pain-free individuals. Journals, books, and audiovisual materials proliferate, and even some of our authoritative textbooks and seminars attempt to legitimize this untenable diagnosis. In this instance, giving a name to the pains has spawned the very symptom amplification and imitative behavior the rheumatologic profession should be combating. This is not a semantic quarrel. The sooner we abandon the diagnosis, fibromyalgia, disband the patient advocacy organizations, and stop the irresponsible publications, the better we serve the public.

Is it any wonder that most treatments, at least the drugs and the obscene neurosurgical interventions, don't really work? One cannot really treat non-diseases. Sympathetic listening, physical activity, maybe cognitive therapy can help, but there are no statistically significant studies to confirm this (although clinical impressions generally agree that these help). Without the dollar poultice, would these patients be separated from the rest of humanity and threaten to bankrupt disability compensation systems in the Western world?

Some have argued that other syndromes besides FM exist without verifiable physical features<sup>5</sup>. Included in that list are migraine headache and dyslexia, among others. But, *pace* Crofford and Clauw, these are well defined conditions with exacting criteria, which FM (and the closely related chronic

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See Fibromyalgia syndrome in an Amish community: a controlled study to determine disease and symptom prevalence, *page 1835*

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fatigue syndrome) lacks. Sensible antagonism to FM and its cognates now graces several books<sup>6-10</sup> and innumerable papers and editorials (too many to be cited here, but referenced in<sup>11</sup>). Eschew the diagnosis and help us prevent “turn[ing] diseases into commodities” or turning common chronic pain in people getting on with their lives into diseases and syndromes. FM is an iatrogenic syndrome because it has to be named by a doctor to exist. More’s the pity that 10 years after Sidney Block’s wise essay, this lesson has not yet been learned<sup>12</sup>.

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