



Not the Last Word

Not the Last Word: Fibromyalgia is Real

Joseph Bernstein MD

Fibromyalgia is a disease characterized by widespread pain, sleep disturbances, and classic tender points. Clauw and colleagues [5] claim that fibromyalgia is based on “changes in the levels of neurotransmitters that cause augmented central nervous system pain processing.” On the other hand, as noted by Wallace [22], some prominent rheumatologists do not believe that the disease exists.

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Hadler's [11] definition of fibromyalgia put it starkly: “There is no disease.”

Why the controversy? You might think that it is because fibromyalgia cannot be found on an objective examination, such as radiograph or a laboratory test. That is true enough, but it really cannot be the right answer. After all, there are many orthopaedic conditions whose defining evidence is so prevalent among asymptomatic people (the MRI findings of partial rotation cuff tears [21] and disc disease [2], to name two) that we cannot truly say that the evidence drives the treatment.

The root cause of the fibromyalgia controversy is that reasonable people can argue that fibromyalgia is more a mind/brain disease than a musculoskeletal disease. But there is more to it than that. For one thing, fibromyalgia patients can easily frustrate us. Their complex presentation requires more time than the typical clinic slot affords. They leave us feeling ignorant because we do not understand them

and feeling impotent because we cannot cure them. They hector us for notes certifying their disability without providing the usual signifiers of legitimacy.

Of course, we have to be open to the possibility physicians can be part of the problem. Maybe our practices have been organized too much around the principles of “clinical productivity.” Perhaps we find ourselves on a pedestal of wisdom we do not deserve. And just exactly why did we accept from society the role of disability arbiter?

With these obstacles removed, we may be a little less vexed by patients with widespread pain, sleep disturbances, and tender points—however they are labeled.

And while labeling is a problem, we have faced that before and moved on. Years ago, the condition of excessive urination was labeled as diabetes. With additional knowledge—specifically, regarding the taste of the urine—the label split into “mellitus” (sweet) and “insipidus” (bland). When the incidence of diabetes mellitus was further noted to have a bimodal age distribution, the label of “juvenile diabetes mellitus” was born. We now know that age is a confounder of sorts: The real pathology of juvenile diabetes mellitus

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lies in the pancreatic islet cells. Does that mean that “juvenile diabetes mellitus” does not exist? Of course not; it (like many other conditions in musculoskeletal medicine [1]) is just poorly named.

Fibromyalgia is real. If nothing else, fibromyalgia has an entry in the 10th edition of The International Classification of Diseases (ICD-10) [15]. Because this code book drives payments, ICD-10 is almost literally a gold standard; a listing there alone imbues a disease with life. It is just the perimeters of fibromyalgia’s existence that must be defined.

Even the defenders of fibromyalgia acknowledge that it is a diagnosis more open to dissembling than, say, an open fracture. Also, as noted, it is possible that fibromyalgia is more psychiatric than musculoskeletal. Last, it must be recognized that some “woeful” [11] patients have been encouraged to anchor their lives around their misery. Yet none of these factors make fibromyalgia any less real. As Vonnegut pointed out, you are who you pretend to be. For people who have enduringly assumed the role of fibromyalgia patient, the disease has them, and not the other way around.

Let us move past that. Let us imagine a world where doctors did not have to worry about their “clinical productivity,” where doctors did not

determine disability or endorse impairments; where doctors did not have to maintain the façade of omniscience. In that world, a patient presenting with widespread pain, sleep disturbances and tender points gets our sympathy and our attention without recrimination.

I do not live in that world; few of us do; but perhaps we should.

One day, we will know more. We might learn that fibromyalgia is a variant of depression or other psychiatric condition. We may discover a molecular etiology. Or we may find out, in retrospect, that fibromyalgia was no more than a medical meme that outlived its usefulness.

Until we know more, we live up to the highest ideals of medicine by focusing on the mitigation of suffering, despite our ignorance. Unfortunately, other ideals may get in the way.

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Dr. Bernstein’s essay is both a plaint and a plea. He is disconcerted by the special demands of caring for a patient bearing the fibromyalgia label and he is concerned that the resulting care leaves much to be desired. There are humanists in the American medical pantheon who spoke to the ethical

challenges of caring for patients with symptoms that defy diagnostic acumen. William Osler [17] and Francis Weld Peabody [18] wrote on this topic. James J. Putnam’s 1899 Shattuck Lecture, which was published in volume 141 of the *Boston Medical and Surgical Journal* (the forerunner of the *New England Journal of Medicine*), was titled “Not the Disease Only, but Also the Man” [19]. To treat these patients, the physician must “comprehend the mental language of all sorts of conditions of men.” Neither physicians, nor these patients who turn to them, have yet to take Putnam’s advice to heart.

Dr. Bernstein quotes me out of context. I did say “There is no disease” in the review of two books I wrote for the *New England Journal of Medicine*. The last sentence reads, “There is no disease to cure” [11]. Fibromyalgia denotes a complex illness narrative laden with idioms that speak to pervasive symptoms and considerable suffering, often far more suffering than is experienced by patients with organ system diseases like heart failure and many cancers. The role of the physician is to comprehend—not to question or denigrate the patient’s veracity or motives—but to understand the context in which they suffer. Since there is no disease to cure, perhaps there is succor to be had in addressing the context.

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Fibromyalgia is not the latest rubric under which this suffering plays out. The latest rubric abandoned sophisticated “tender points” [23]. “Central sensitivity state” implies that the experience of suffering has central neurophysiologic correlates. Of course it does; this is a tautology unless one ascribes to vitalistic notions. However, our tools for dissecting these correlates are imaging modalities that are too blunt to be reliable or specific. Furthermore, the implication of this approach has pejorative baggage. Can we say that this illness experience is “in your mind” without infuriating the patient? Not today, not yet, given the social construction of “in your mind” and the social construction of “fibromyalgia” [13]. To most patients “in your mind” is yet another assault on their self-esteem, which is already beleaguered. It drives these patients toward sectarian practitioners who have no proclivity to challenge them, and little if any success in returning them to their premorbid state.

Part of the experience of any illness that defies definition of etiopathogenesis is that many in the patient’s community question the validity of the idioms of distress. This colors the relationship between the afflicted and family members, coworkers, and caregivers. Furthermore, it thwarts healing; if you have to prove you are ill, you cannot get well [9]. This

dialectic plays out with viciousness in the medicolegal context [10]. Whether the issue is disability determination or causality, as is the case in tort proceedings or workers’ compensation claims [12], the only predictable outcome is social iatrogenesis.

The illness that is labeled “fibromyalgia” is as well-studied as any “incurable” illness we face, better than most. Patients do not have fibromyalgia or suffer from fibromyalgia, they suffer fibromyalgia. We would not toss a patient with multiple sclerosis or rheumatoid arthritis into a societal maelstrom as we have those who suffer fibromyalgia. We need to change the social construction of illness that countenances this fate. Perhaps then we can forewarn if not prevent a dreadful clinical outcome. Until then we need to take our place as ethical, caring and trustworthy physicians at their bedside [8].

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I applaud Dr. Bernstein for taking the position he has, because for too long physicians have disrespected individuals with conditions such as fibromyalgia. I become extremely frustrated when I have given lectures in front of medical students or

residents about the latest findings regarding the pathophysiology and treatment of this condition, only to have them go on an orthopaedic or neurosurgery rotation and witness the “eye roll” by an attending physician when they encounter such a patient in the clinic or hospital. A single eye roll can undo hours of education. It gives that physician-in-training permission to disrespect and denigrate these patients—in spite of overwhelming evidence [6, 14] that there are strong neurobiological underpinnings to this disorder.

Fibromyalgia is a real disease. Of course, there are still doubters in the literature. In the pain field, fibromyalgia is not only viewed as a legitimate disease, but even more so as the poster child for a common type of pain—pain that originates more so from the brain and central nervous system than ongoing tissue damage or inflammation. Why is it so difficult to believe that pain can originate from the brain? We accept phantom limb pain. We accept headaches. In fact, most highly prevalent chronic pain conditions (fibromyalgia, headache, irritable bowel, interstitial cystitis, TMJ disorder, etc ...) are now thought to be much more so originating from the brain than from peripheral tissues.

I am not at all singling out orthopaedists for not believing in fibromyalgia, because most

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rheumatologists (of which I am one) similarly are uncomfortable caring for these patients, just as gastroenterologists are with irritable bowel syndrome, urologists are with interstitial cystitis, or dentists are with temporomandibular joint disorder. Every specialty has one or more diagnostic labels for individuals who present with pain or other unpleasant sensory experiences in the body regions they are responsible for that defies their classic understanding of pathophysiology.

The reason for this discomfort is largely because the problem is not in the tissues or organs you learned about in training. Instead, the problem is that the volume control for sensory processing is turned up in the brain. These individuals feel any sensory experiences as more painful or unpleasant than would normally occur with that degree of tissue damage. This increased volume control or gain has been repeatedly demonstrated using both sensory testing and functional neuroimaging, and occurs in subsets of any group of chronic pain patients—no matter what the underlying disease is that is causing the pain [6]. One of the historical concepts regarding fibromyalgia that was quite incorrect is that this is not “yes” or “no.” Different individuals in the population have differing gain or volume control settings for sensory

processing in their brain, and the higher this is, the more pain is coming from the brain (i.e., centralized) versus the periphery. The end of this continuum is fibromyalgia.

Practicing orthopaedists can continue to ignore the latest literature on fibromyalgia – at their peril (and to the detriment of their patients). Recent studies by Brummett et al. [3, 4] have clearly demonstrated that as individuals with osteoarthritis undergoing knee or hip arthroplasty have increasing centralization of pain (as measured by the 2011 Fibromyalgia Survey Criteria), they become strikingly less responsive to surgery meant to improve pain, and to opioid analgesics. These strong effects are independent of, and much stronger than psychological factors, not at all confined to the end of this spectrum that we label as having fibromyalgia. Orthopaedists and other proceduralists should assess where individuals are on this continuum either by understanding how to identify this type of pain during their history and physical, or by administering the new fibromyalgia self-report measure [16]. This information is critical as you attempt to determine how much of an individual’s pain is occurring because of a problem in the region of the body where you are contemplating operating, as well as how much is coming from superimposed brain pain amplification.

Orthopaedists should not be primarily responsible for caring for fibromyalgia, but please “first do no harm.” Eye rolls are no longer acceptable (what other group of patients do we feel comfortable denigrating?), and surgery and opioids should be used with extreme caution. There are a plethora of drug and nondrug treatments that can be effective for this type of pain [6, 20], but the routine care of these issues is probably best left to primary care physicians or pain specialists.

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Dr. Bernstein observes that “fibromyalgia is real,” and “fibromyalgia patients frustrate us.” I think no medical practitioner would argue about the second statement, some might like to argue about the first, splitting hairs on the meaning of “real” and words like, “disease.” But if five million persons in the United States, or 10% of an “at risk” population of middle-aged women, present with a particular pattern of symptoms, which has been given a name, certified by the US government as having an existence, and meriting disability awards, does it make sense to argue, “it’s not real?” Like it or not, fibromyalgia has come to stay, and we must face what can be

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done about it, not turn our minds to, “Should it have happened?”

But why did it happen? What’s the origin of the word?

Bernard of Clairvaux wrote, “Hell is full of good wishes.” It was those “good wishes” that motivated a group of well-meaning physicians in 1990 to set up criteria to explore the problem of “fibrositis” [24], which they knew was a misnomer because, unlike rheumatoid arthritis, there was no inflammatory “itis” component in the patients who came to them with complaints of widespread limb pain. The physicians changed the name (always a misrepresentation of progress) to “fibromyalgia.” Subsequently, it has been agreed [7, 23] that two-thirds of that name was also wrong. Yes, there is pain (“algia”), but no, there is no abnormality found in collagen or muscle fibers.

Since it was to be a research study, the committee had to select criteria from among the plethora of symptoms, and so was born “non-restorative” sleep and the bizarre “tender points schedule” [23]. All perfectly reasonable as criteria for a research project, but nonsense for yay or nay diagnostic criteria—if you have 11 of the 18 points found to be tender you get a disability pension for life, but if only 10 are tender you go home empty handed. How could the profession ever

have let it get itself into that nonsensical quagmire?

It has taken a quarter of a century, but there is now expert (but not non-expert) recognition that the criteria for research are not applicable to clinical practice, a conclusion pioneered by Wolfe [24], who was a member of the 1990 committee, and for which there was initially considerable opposition.

Current thinking takes us only slightly forward from the 1990 square one. There is no inflammation, there are no reliable physical signs, laboratory and imaging studies serve only to rule out other conditions, and it is agreed by knowledgeable persons that such testing should be kept to a minimum. The very name of fibromyalgia is nonsense, and has been counterproductive in understanding the patients who generally have many more than musculoskeletal symptoms, but those get neglected due to an inappropriate focus. We ought to call it the “Pain not yet determined syndrome,” but changing the name will not indicate progress.

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