Fibromyalgia: A Short Commentary

Received: September 23, 2016; Accepted: October 05, 2016; Published: October 15, 2016

Keywords: Fibromyalgia; Criteria positive fibromyalgia; Fibrositis; Neurobiological; Temporomanibular; Biopsychosocial

Short Commentary

75% of Persons in the General Population Diagnosed with Fibromyalgia Don’t Have It, But It Is Worse Than That...

In studies of fibromyalgia in 2015 and 2016, we applied fibromyalgia criteria to the 2012 National Health Interview Survey (NHIS), the principle source of information on the health of the civilian US population, and observed that 75% of persons in the US population reporting a physician diagnosis of fibromyalgia did not satisfy fibromyalgia criteria [1,2]. Persons with a fibromyalgia diagnosis who did not report symptoms specific and severe enough to satisfy diagnostic criteria constitute 1.3% of the US population. We will call this group criteria-negative fibromyalgia (C- FM). These persons were nearly exclusively white women (82.2% white, 92.7% women).

Criteria positive fibromyalgia (C+ FM), persons reporting symptoms severe and specific enough to satisfy fibromyalgia criteria positive fibromyalgia was prevalent in 1.7% of the US population. The C+ FM group was much less exclusive, with no ethnic predisposition and a more modest gender disparity of 2.3:1. However, only 27% of the C+ FM group also had a physician diagnosis of fibromyalgia [0.5% of US population]. We will refer to this less common instance when criteria positivity and physician diagnosis occur together as FM++.

Although the prevalence percentages seem small, the absolute numbers of people affected by our findings are not. By our calculations almost 3 million people who do not meet fibromyalgia criteria have been given a fibromyalgia diagnosis. At the other end of the spectrum, there are almost 3 million persons who satisfy fibromyalgia criteria, but have not been diagnosed with the disorder by a physician. It appears likely that many of their physicians when presented with the opportunity to diagnose fibromyalgia decline to make such a diagnosis. Data such as these call into question the usual 2-4% population estimates of fibromyalgia, and the validity of previous epidemiological studies of fibromyalgia that were not designed to identify physician diagnosis. We expect that the majority of the subjects considered to have fibromyalgia in these studies had not been diagnosed as having fibromyalgia.

Our observations in the NHIS of large numbers, apparently over and under diagnosed subjects including that C- FM is far better predicted by demographic factors than symptom reporting, offer essential insights into the nature of historical and contemporary fibromyalgia. Whether fibromyalgia is determined by the tender point examination of the 1990 fibromyalgia criteria or by the symptom assessment tools of the 2010/2011 criteria [3,4], fibromyalgia assessments are always subjective; they are influenced by biologic, psychosocial and environmental factors and, in clinical settings, by the beliefs and biases of physicians and patients. A C- FM diagnosis of fibromyalgia can legitimize vague and difficult or distressing symptoms, allowing entrée into official diagnosis and government approved treatments, or providing a way toward official disability status. All doctors and patients have to do is agree on the diagnosis. There is no reliable way to dispute such a diagnosis, and such a C- FM diagnosis can be “helpful” to the patient and to the physician who struggles to handle a difficult problem and sometimes a difficult patient.

The utility of a C- FM or a FM++ diagnosis depends on a general societal acceptance of fibromyalgia as a “real” disease. Fibromyalgia is one of a series of contested illnesses whose “nature and existence are contested as to whether they are primarily mental, psychiatric, or biological. They are causally undetermined: Their etiology is likewise contested as to social, genetic, toxic and personal possibilities.” “They have fuzzy boundaries and are each cross-linked to other emergent illnesses as subsets, mistaken diagnosis, and comorbid conditions. They are legally explosive: Each condition is caught up in court battles,
For patients, there is a battle to establish and sustain the legitimacy of fibromyalgia, as “society does not readily grant permission to be ill in the absence of disease” [6].

The current dominant paradigm holds that fibromyalgia is a central pain disorder in which there is only a small role for psychosocial and environmental determinants [7,8]. Such a viewpoint is not consistent with the NHIS results or the long history of expansions and contractions of similar somatic illnesses. It is wise to remember George Ehrlich’s admonition: “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” [9]. One of the implications of Ehrlich’s statement is that the diagnosis of fibromyalgia is discretionary, and that patient level psychosocial factors and external societal factors influence that discretion.

A C- FM diagnosis requires that the physician buy into the fibromyalgia concept. With C+ FM this buy-in does not occur or is only partial. Many persons (C+ FM) who satisfied NHIS criteria for fibromyalgia reported receiving alternative diagnoses, such as rheumatoid arthritis (15.3%), gout (3.3%), lupus (1.4%), low back pain (21.7%), and non-specific “arthritis” (47.5%) [1,2]. The constellation of severe symptoms can be clinically interpreted and diagnosed in many different ways, perhaps influenced by clinician and patient beliefs and their resultant interactions. Published diagnostic criteria appear to be ignored in C+ FM and used only as a vague guide in determining what fibromyalgia is in clinical practice (C- FM, FM++).

What these data mean, practically, is that psychosocial and environmental forces, physician and patient’s beliefs strongly affect fibromyalgia diagnosis and status. The distinguished medical historian Edward Shorter characterized fibromyalgia as a “psychic epidemic, an illness attribution that spreads epidemically, and then is forgotten.” We have previously noted that the growth of fibromyalgia and its precursor, fibrositis, began in the 1980s [10], after years of virtual neglect following the 1904 description of fibrositis [11] and the veritable shutdown of the fibromyalgia lookalike, neurasthenia, which was complete by 1930 [12,13]. The neurasthenia shut down followed loss of societal support with the recognition that neurasthenia was not a condition of over-sensitive reflexes and was better considered within a psychological framework [14,15].

Somatic symptoms and syndromes have always existed, but what drives the modern diagnosis of fibromyalgia?

Three essential stakeholders:

1) The pharmaceutical industry (Pharma);
2) Physicians with intellectual conflicts of interest (COI) and ties to Pharma;
3) Patient support organizations.

In trying to understand why fibromyalgia over diagnosis (C- FM) exists, we noted that a recent five-year study of health care utilization in the US military observed an increase in fibromyalgia prevalence from 0.307% to 0.522% [15]. The authors stated “…we strongly suspect that the rise in FMS prevalence between 2006 and 2008 is due to drug marketing activities between September 2005 and October 2008, the period when Pfizer “illegally promoted the sale and use of Lyrica [pregabalin] for a variety of off-label conditions (including chronic pain) [and] offered and paid illegal remuneration to health care professionals to induce them to promote and prescribe Lyrica ...” “By 2008, manufacturers of these drugs began direct consumer marketing and increased grant monies for FMS provider education and research, and for FMS advocacy groups .... In 2008, Pfizer provided about $4 million in grants to US physicians, nurses, and other health professionals to educate them about FMS. Coinciding with these marketing costs are FMS clinical guidelines developed by consensus and literature reviews. The 2009 guidelines, based on a meeting funded by “an independent educational grant from Pfizer,” were developed by US experts with documented conflicts of interest with manufacturers of FMS-approved drugs.”

Pfizer-sponsored publications state that “Although awareness and understanding of FM have improved, it is thought that FM remains undiagnosed in as many as 3 of 4 people with the disorder (Data on file. Decision Resources report 2009. Pfizer, New York, NY)” [7,8]. Such articles then point out the presumed medical hazards of delayed diagnosis and go on to advocate active treatment: “Better health outcomes and quality of life can be achieved by patients with FM with effective treatments developed as a result of an enhanced understanding of the disorder. Clinicians, both individually and in collaboration with other health care professionals and their patients, can improve patient care with vigilance recognition and diagnosis of FM.” — The conclusion of the Pfizer organized and financed “Fibrocollaborative” with “editorial support” also funded by the pharmaceutical company [8] while these paragraphs on the extensive role of Pharma are incomplete; a large literature exists that the reader may consult [16-20].

The evidence that current medical practice has led to better health outcomes is non-existent; the general ineffectiveness of pharmacological therapies outside of the clinical trial setting has been well characterized by meta-analysis [21,22] and longitudinal population [23] and insurance database studies [24]. Our data show that there a millions of potential customers provided more physicians can be taught to diagnose fibromyalgia, a job that has been done very well so far by Pharma.

Physician support for fibromyalgia has been a very important force, as it has driven acceptance of the idea of central pain and a neurobiological basis of fibromyalgia [25]. However, there is no evidence that central neurological alteration is the cause of the pain of fibromyalgia; all findings to date have been derived from cross-sectional studies unable to determine whether the observed difference reported represents a risk factor, an epiphenomenon, an endophenotype, or is causal [26]. Despite the frequent claims that the rapid pace of neurobiological discovery means that definitive proof is right around the corner, the prospective studies needed to investigate fibromyalgia causality still await conception. The single attempt to prospectively understand the neurobiological mechanisms of “central pain” disorders was the OPPERA study of temporomandibular disorder (TMD), which concluded that ‘TMD is a complex disorder with multiple causes consistent with a biopsychosocial model of illness’ [27]. Failure
to demonstrate a reducible neurobiological causality, along with a host of anomalous observations that are not consistent with central sensitization [26,28-30], has been willfully ignored or fought against. It remains hard to find “academic” articles that move beyond the idea of “central pain” or that consider a strong bio-cultural [31] or complex systems component to the disorder, although important publications exist that do this [32].

The role, physicians play in publishing data on fibromyalgia must be mentioned. Index Medicus now (September 2016) lists 9,366 article addressing fibromyalgia, and the tangible and intangible benefits physicians receive from publishing are substantial [18,33]. Why do independent investigators do fibromyalgia studies? Because it is easy to find patients and there are always abnormalities. If you look hard enough almost any questions can seem publishable and justified as an incremental increase in scientific understanding.

Finally, there has been an enormous and often quite successful effort by patient support groups to legitimize fibromyalgia and support fibromyalgia physicians. These efforts have been documented elsewhere [19,34-36]. For patients and their advocates, the suffering of fibromyalgia is a self-evident demonstration of legitimacy, even if the scientific reasons used to establish its medical legitimacy may not be.

We acknowledge some limitations to the NHIS study. Our data refer predominantly to the United States. The NHIS data used surrogate fibromyalgia criteria that we developed and validated. It is likely actual criteria, had they been available, would led to modestly different results. In addition, in writing about C- FM, some cases might include previous FM++ subjects who improved to the extent that they now longer satisfied criteria. Studies in the clinical literature suggest this may be a much as 25% of criteria negative subjects. However, in the NHIS setting that percentage is likely to be lower and certainly not higher.

In summary, the majority of clinical fibromyalgia cases in the US do not reach levels of severity considered to be diagnostic. Rather, fibromyalgia is disproportionately dependent on socially-constructed factors rather than the symptoms themselves. Diagnostic criteria appear to be used only as a vague guide by clinicians and patients, allowing for substantial diagnostic expansion of fibromyalgia.
References


