

## Editorial

### Labeling Woefulness: The Social Construction of Fibromyalgia

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Increasingly, patients suffering a life colored by widespread pain and misery are labeled as having fibromyalgia. Yet, fibromyalgia is one of the most impenetrable and controversial labels in medicine today. The construct flourishes despite many failed attempts to provide compelling biologic or clinical underpinnings. In this essay, we explore the fashion in which its social constructedness explains its persistence. We show how a wide range of actors, deeply committed to its perpetuation, collaborated to usher fibromyalgia into modern parlance as a genuine disease. Some rheumatologists carry the banner; so do patients in desperate search for a meaningful, socially acceptable (*i.e.*, biologically based) label for their pain. They are joined by powerful social forces such as pharmaceutical firms and the media.

This essay argues that however well it serves its adherents, the fibromyalgia construct poses dangers for patients so labeled and for those likely to suffer that fate. The contagion of the concept reflects the medicalization of psychosocial problems for which biomedicine has few solutions. We propose an alternative social construction for persistent widespread pain that makes it acceptable for patients to seek solutions in modulating the predisposing psychosocial hazards rather than persist in the belief that the solution must reside in neurobiology. We propose that a public examination of the social construction is ultimately more likely to prove palliative than any exercise in medicalization.

In developing this thesis, we take advantage of scholarship that takes the role of medicine in society as its subject. Central to this work is the notion that while the root cause of “disease” may reside in pathobiology, the experience of illness is socially constructed. Illness is suffered in a fashion that reflects input from groups of people operating in particular historical contexts and out of specific intellectual, economic, and other shared interests. There may be aspects of pathobiology that generalize across time and peoples, but little is fixed about the illness experience or the fashion in which it is labeled.

Furthermore, much that is termed pathobiology is socially constructed. That assertion may come as a surprise

in the ethos of molecular biology, but it shouldn't. The scientific conceptualization of “abnormal” is also in the eyes of the beholder, even in the eyes of the beholder who is modeling the descriptive statistics. Race, normal sexual behavior, kinship, and authorship are notions that have proved mutable in recent memory. Likewise, determining who qualifies for elements of the “metabolic syndrome” is a moving target. Since each of these ideas reflects particular intellectual, economic, and other interests and operates in particular historical contexts, they too belong among the myriad “social constructions” that color our lives.<sup>1</sup> Important for our argument, the form of the social construction always has material effects on patients' perceptions and bodily sensations.

Most diseases are both *real*—they cause pain and suffering; and *socially constructed*—their particular formulation reflects the social and historical context in which they are made. We will argue that in the case of fibromyalgia both the disease and the illness experience are real and socially constructed: No one has fibromyalgia. No one suffers from fibromyalgia. Instead, there are patients who suffer fibromyalgia.

#### ■ A Brief History of the Social Construction of Fibromyalgia

It was only a century ago that medicine drew a distinction between “articular rheumatism” and “muscular rheumatism.”<sup>2</sup> One consequence is the enormous progress in the understanding of the inflammatory and noninflammatory arthritides. “Muscular rheumatism” has yielded its secrets more begrudgingly, but not for lack of importance or of effort on the part of clinical investigators.

“Fibrositis” was coined in 1904 by no less a luminary than Sir William Gowers of University College Hospital in London while expounding on his own lumbago.<sup>3</sup> If sciatica was a form of “neuralgia,” he reasoned, lumbago was a special form of muscular rheumatism which he inferred to be an example of muscular fibrositis. Furthermore, fibrositis could involve other regions and spread to adjacent structures. He wrote that the “brachial form is extremely obstinate,” commonly presenting as a “stiff neck.” For therapy, heat, massage and salicylates could be supplemented by “counter-irritation” and “the deep hypodermic injection of cocaine, repeated daily for 2 or 3 weeks.”

A contemporary of Sir William, Professor Stockman of Edinburgh, palpated “indurations” in the painful regions, described corollary histopathology, and suggested an infectious etiology.<sup>4</sup> The idea that inflammation was causal was debunked in 1940 by Collins<sup>5</sup> who reexam-

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ined Stockman's specimens and added his own series. The inflammatory theory was rapidly superseded by the notion of painfully edematous fat lobules formulated by Copeman and Ackerman.<sup>6,7</sup> By the time Wallace Graham established the North American foothold for "fibrositis" in Toronto in 1950,<sup>8</sup> there was no unifying pathogenetic theory. Graham argued that the term should not be applied to all soft tissue rheumatism, only to patients whose chief symptoms were "pain, stiffness, and soreness. . . most frequent sites are in the lower back, gluteal, neck, shoulder, and chest areas." "Fibrositis," Graham argued, "is not a disease entity but a syndrome brought about by a variety of widely separate conditions."

Fibrositis, its advocates, and its adherents were to spend the next 35 years in relative obscurity. There were luminaries such as Graham's successor in the Toronto school, Hugh Smythe, who labored to render fibrositis less ephemeral a concept,<sup>9</sup> and Janet Travel<sup>10</sup> whose therapeutic inventiveness was afforded to President Kennedy. There were polemics and the occasional systematic study addressing such concepts as "tender points," "trigger points," "psychogenic rheumatism," and the like.<sup>11</sup> But fibrositis remained in the background as other clinical issues captured the attention of academic rheumatologists and their students.

Fibrositis would probably have remained on the fringe were it not for the initiative in the mid-1980s by Merck, Sharp and Dohme, Inc. to expand the indications for cyclobenzaprine hydrochloride (Flexoril), its novel putative muscle relaxant, to fibrositis. Merck underwrote a symposium on the topic and the formation of a new Committee of the American College of Rheumatology. In both instances, thought leaders in the field were brought together to examine the science and lack thereof relating to fibrositis. The work product of the symposium was published in 1986 as Supplement 3A in Volume 81 of the *American Journal of Medicine*. The work product of the Committee is the semantic, fibromyalgia, and the much publicized "American College of Rheumatology 1990 Criteria for the Classification of Fibromyalgia."<sup>12</sup> To be so classified, the patient had to have persistent widespread pain and an exquisite aversion to being palpated in 11 of 18 specified anatomic sites. The criteria have weathered poorly. That's not surprising since they are the product of circular reasoning: they were derived from the same population from which the hypothesis was generated. The quantification of tender points has proved such a sophistry that even the lead author of the criteria has decried their use in the clinic.<sup>13</sup> Absent "tender points," the criteria suggest that anyone with persistent widespread pain qualifies for labeling as suffering from fibromyalgia.

The promulgation of criteria under the imprimatur of the American College of Rheumatology was a crucial moment in the historical construction of fibromyalgia as a bona fide disease. It has legitimated fibromyalgia in the eyes of many clinicians and of the medicolegal establish-

ment. It has vindicated patients whose misery was confounded by so many who doubt symptoms can be "real" in the absence of demonstrable disease. It has led to an explosion in the diagnosis. And it has caused a number of investigators to turn their attention to the epidemiology of persistent widespread pain. "Fibromyalgia" has gained such advocacy that on June 30, 1999 a Resolution was introduced in the U.S. House of Representatives (HR 237 IH). It recognized "the severity of the issue of fibromyalgia" defined as a "chronic disorder characterized by widespread musculoskeletal pain and tenderness"; which "may be triggered by stress, trauma, or possibly an infectious agent in susceptible people. . . ."

In this way, a tenuous, impenetrable, unproved construct has been promulgated, advocated, widely accepted, and codified. Fibromyalgia has been socially constructed as a biologic disease.

### ■ Fibromyalgia and Medicalization

Medicalization occurs whenever a set of social problems is reformulated as a medical problem. This entails labeling as a disease with the presumption of some underlying pathobiology on which therapy can be based. Since the time of Sydenham,<sup>14</sup> in the early 18<sup>th</sup> Century, medicine was charged with determining the disordered anatomy or physiology, the *disease*, that underlies any set of symptoms, the *illness*. In the early 20<sup>th</sup> Century, medicine assumed an expanded role as the arbiter of behaviors in society that were consonant with particular *disease* states. Medicine was called on to define the illness that could be ascribed to any disease. In this fashion, physicians assumed responsibility for medicalizing work absenteeism and long-term disability.<sup>15</sup> Medicalization is a social force that reached its peak in the 1970s when physicians assumed the role of determining whether symptoms were consonant with preconceived notions of illness rather than preconceived notions of the consequence of disease. Symptoms that were deemed consonant were "real" as opposed to deviant symptoms, "functional complaints," or "illness behaviors." The chroniclers and analysts of this dialectic include Freidson<sup>16</sup> who spoke of medicine's "professional dominance" and Star<sup>17</sup> of its "cultural authority." This is a cultural hegemony based solely on conviction.<sup>18</sup>

In 1976, Ivan Illich warned about the "medicalization of life,"<sup>19</sup> a warning that has proved prescient.<sup>20</sup> Medicalization grows more and more inventive, now encompassing kinship in the promise of genomics<sup>21</sup> and misery in the promise of "fibromyalgia."<sup>22</sup>

### ■ The Epidemiology of Persistent Widespread Pain

Based on community surveys in many countries, Britain<sup>23</sup> and Israel,<sup>24</sup> for example, more than half of us is hurting today or recalls pain in the past month. Regional musculoskeletal disorders account for much of this morbidity. For half of these people, these morbid experiences are self-limited and, while they may be daunting at the time, are soon forgotten. Unfortunately, for the other

half the experience of pain is less remittent; for many it is unrelenting and often involves more than one anatomic site. Persistent widespread pain afflicts about 10% of the populations of Norway,<sup>25</sup> Australia,<sup>26</sup> Britain,<sup>27</sup> Germany,<sup>28</sup> and wherever else surveys have been performed. Our long-suffering compatriots are more likely to be mired in the lower socioeconomic strata,<sup>29</sup> tend to be unhappy and anxious,<sup>30</sup> and suffer symptoms that they interpret as indicating that more than their musculoskeletal system is diseased.<sup>31</sup> They feel compelled to frequent primary care practices the world round,<sup>32</sup> although whether they are considered depressed or just unhappy depends on the prevailing definitions of affective states.<sup>33</sup> Most will not qualify for labeling as suffering a primary affective disorder. For example, in Britain the coincidence of such in the population with persistent widespread pain is not much greater than the prevalence in the overall population.<sup>34</sup>

For most some relief is in sight. Their natural history, with or without the ministrations of caregivers, is one of waxing<sup>35</sup> and waning,<sup>36,37</sup> although they are not likely to find themselves pain free<sup>38</sup> and particularly unlikely if they happen to be referred to or feel compelled to attend rheumatology clinics that specialize in “fibromyalgia.”<sup>39</sup> This descriptive community-based epidemiology suggests a range of individual differences in the experience of regional musculoskeletal pain, rather than distinctive populations or a distinctive subset. A similar conclusion can be drawn from analyses of the attributes of people with persistent widespread pain who elect to become, or feel they have no other option than to become patients with persistent widespread pain.<sup>40,41</sup> What distinguishes people in the community with persistent widespread pain from patients with persistent widespread pain is the magnitude of psychological distress associated with the pain rather than its nociceptive quality. People with persistent widespread pain choose to seek care when the painfulness is insufferable.

If chronic persistent pain is within the range of normal human experiences, albeit at the unpleasant extreme, is it abnormal? If it is an experience that the person finds tolerable, or tolerable for a time, is that person abnormal? There are telling analogies. For example, if one is persisting at great personal cost, at great personal “pain” if you will, in an unsatisfactory intimate relationship or job, should we label that person abnormal? Epidemiology is hard pressed to define such boundaries; there are simply too many variables. If there is an operational definition, it is that the suffering is insufferable to the sufferer and/or for those in the sufferer’s intimate community. How can physicians and patients construe the situation outside of the dominant construct that fibromyalgia is a biologic and biomedically legible construct? What therapeutic contract can be initiated with a complaint of “I can’t stand it any longer” and elicit the diagnosis that “Your pain is insufferable?” What do we call the state of medically inexplicable insufferable physical symptomatology? This is not the same pain or pain state that is

reflexively aversive, opiate responsive, difficult to express in language, even unspeakable.<sup>42</sup> It is generally accepted that this is an opiate unresponsive,<sup>43</sup> emotive state that provokes dramatic narratives of distress.

### ■ **Becoming a Fibromyalgic: Transformations in Identity and the Dangers of Iatrogenicity**

However welcome the label may be, it tends to have powerful and often unrecognized effects on those so labeled. The most fundamental is on one’s identity, one’s sense of self. From being a whole person with many life options, the fibromyalgic is often transformed into a long-term patient whose life is dominated by, and limited by, disease. Becoming a fibromyalgic requires the rewriting of one’s illness narrative.<sup>44</sup> This new narrative of distress is always laced with idioms that are learned and used to mark the experience. Much is learned in the course of treatment. Physicians can silence their patients and rescript their narratives, thereby causing their medical self-stories to conform to a preconceived notion of the manifestations of any given disease.<sup>45</sup> Patients with chronic regional musculoskeletal disorders learn to score their pain as global and acquire idioms of distress that are peculiar to this clinical situation. Patients labeled with fibromyalgia, when compared with patients with rheumatoid arthritis, express pessimistic beliefs about themselves and others, assuming the worst possible outcomes.<sup>46</sup> They consider themselves more ill than is the perception of patients suffering emphysema, rheumatoid arthritis, even advanced cancer.<sup>47</sup> For many of these patients, fibromyalgia is no mere social construction; it has transformed into real, pervasive, awful bodily sensations.

### ■ **Suffering and Public Health**

Some 10% of people living in the community spend every day coping with widespread pain. Most have all sorts of financial and personal stresses. These people live or can live lives that are less pleasant, and less lengthy. They should be a great concern of any public health agenda.

Much of this is a matter for the body politic; much relates to economics and job satisfaction,<sup>48</sup> but not all. Medicalization lurks for any of these people who find bodily symptoms pervasive whenever life courses out of their control. Uncertainty as to healthfulness will transform into certainty as to their fate as the victim of some disease that medicine has yet to identify. It is not the pain that drove them to seek medical care; it is the suffering consequent to the uncertainties the pain precipitates in their mind. It is suffering that is their chief complaint. It is suffering that demands recognition and care. When people with persistent widespread pain seek care, it is because they have exhausted their wherewithal to cope and are casting about for attention to their suffering. Isn’t “cognitive behavior therapy” a sophisticated attempt to educate these adults in self-awareness and in finding and choosing accessible alternatives in life? Can’t medicine learn to provide such as part of a treatment act? If med-

icine can't provide such,<sup>49</sup> these unfortunate patients should seek it elsewhere, perhaps in counseling to find and address some of the psychosocial sources of their distress. However, effective caring will prove elusive until it is realized that fibromyalgia is the social construction for their suffering.

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