

“Fibromyalgia” and the Medicalization of Misery



The burden of musculoskeletal symptomatology in the community is considerable¹. Regional musculoskeletal disorders predominate². If questioned closely, nearly all of us can recall low back pain last year, a third of us recall pain at the shoulder, hand or wrist, and 15% of us at the elbow. These memorable episodes last at least a week and often are recurring. Regional musculoskeletal pain is an intermittent and remittent predicament of normal life. Feeling “well” demands the sense of invincibility that we can cope with our next musculoskeletal morbidity. Being well symbolizes our triumph that we had the wherewithal to cope with the last episode for as long as it took for that episode to remit, to cope so well that the episode is barely memorable, if at all. Being well does not mean avoiding the challenges of regional musculoskeletal disorders; that is not possible. These challenges are as much a part of life as heartache, heartburn, headache, and the like. Therein lies the enigma of health³.

It has long been common sense that a press to recourse is driven by the physical intensity of the predicament. The more severe the pain, the more likely it is memorable, the more likely one is to consume analgesics, the more likely one is to experience work incapacity, and the more likely one is to seek professional care. Epidemiology has put this common sense to the test. It is not tenable. Compromise in the wherewithal to cope with the regional musculoskeletal disorder supersedes pain and biomechanical compromise in driving our response. The science supporting this assertion is now as compelling for the predicament of upper-limb pain^{4,5} as it has been for low back pain for over a decade². That explains the results of a World Health Organization (WHO)⁶ survey of primary care practices around the world. The 22% (ranging from 5.5 to 33%) of patients in these practices who reported persistent pain were 4 times more likely to suffer anxiety or depression than patients without persistent pain. These people are choosing to be patients because their ability to cope with their pain is overwhelmed

by confounders that lurk in the psychosocial context in which the pain is suffered.

This insight has emerged largely from studies of the plight of people in the community with discrete regional musculoskeletal disorders. Does the same insight pertain to the people, hidden in all these surveys, with persistent pain at multiple sites? Only recently has their plight been recognized. They are more likely to manifest psychological disturbance and to report other somatic symptoms than people who suffer from, or recall discrete regional disorders⁷. They are miserable and driven to seek medical care frequently⁸. The report by White and Thompson in this issue of *The Journal* demonstrates that 7% of the Amish community lives under this pall despite taking pains to stay out of the mainstream of life in North America⁹. This prevalence is similar in the other populations surveyed by White and Thompson and in many populations surveyed elsewhere. People with persistent widespread pain are bedeviled by life challenges that may render Sisyphean any quest for some sense of being well, let alone sense of invincibility. The intermittent and remittent morbid predicaments of life that the well find surmountable are insufferable and unforgettable setbacks for those living under this pall. Hence, they take note of and report other somatic symptoms⁷. Variations in bowel habits are very concerning, and diminished vigor seems oppressive. There is no *joie de vivre*.

I suspect that few suffering with persistent chronic pain are suffering in silence. I suspect that their narrative of distress is very dependent on the listener. The idioms of distress that would enlist the empathy of a clergyman are hardly the same as those that might enhance communication with a social worker, a sibling, or a physician. We have no data as to how these people select a confidant. They probably choose many and often, depending on the cultural setting. If they are seduced by the construction, “scientific medicine,” they will choose a physician. As White and Thompson point out, the Amish are long imbued with this

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

notion and not averse to seeking medical care when that seems reasonable to them. The medical contract demands specific treatment for the cause of the pain. Such a treatment act rests on the shakiest of scientific grounds for the patient with a regional musculoskeletal disorder^{2,5}. It is groundless for the patient with persistent widespread pain. I suspect this is because typical treatment acts overlook the compromised coping that causes patients to seek care in the first place¹⁰. Nonetheless putatively scientific treatment acts abound. All are circular exercises that commence with a ranking of symptoms, then futilely probing for pathology before applying neologic diagnostic labels that are but reiterations of the presenting symptoms. All the while, the treatment act is plying the patient with intimations as to the pathophysiology of their nociception. That is how the person suffering persistent widespread pain learns to be a patient with “fibromyalgia” (FM). The clinician who applies the label and promulgates the treatment act must disregard the observation that “tender points” are related to generalized pain and pain behavior¹¹. The patient is forever changed. Their narrative is laced with the clinical heuristics they have learned, which they can recite with objectivity that approaches dispassionate.

The fate of patients with persistent widespread pain labeled as FM stands in reproach to whatever theory underpins this sophisticated treatment act. In the community, the majority of people with persistent widespread pain improve with time¹². That is not the fate of those who become patients and are labeled FM. Based on the science that pertains to the regional musculoskeletal disorders, I would suggest that this unhappy fate is not solely a reflection of the intensity of their symptoms or the pervasiveness of the psychosocial factors that confounded their coping so that they chose to be patients in the first place. I would suggest that the treatment acts, dripping with empty promises of elucidation and unproved promises of palliation, are iatrogenic. I would further suggest that these circular treatment acts will exacerbate whatever mood or thought disorder is complicating the plight of these patients¹³.

There is no more valid a diagnostic label for patients complaining of persistent widespread pain than “overwhelming persistent widespread pain.” FM and its sister labels^{2,14} means no more than that. “Functional somatic syndromes”¹⁵ and “medically unexplained symptoms”¹⁶ denote the same subset of the woebegone. The former is difficult to define, even by its proponents, and the latter implies that one would be better off if symptoms are medically explicable.

The proponents of the FM construction are convinced that their pathophysiological insights and theories are valid, albeit as yet unproved, and their therapeutic approaches need but tweaking to produce the benefit that has eluded demonstration to date. I am concerned that this approach is causing harm today. However, it is possible that a thera-

peutic triumph is but one scientific discovery away, rendering my psychosocial and sociocultural synthesis secondary, if not fatuous. After all, one might be inclined to construct sociocultural models for the pathogenesis of pulmonary tuberculosis and AIDS were it not for the superseding microbiology. That is why many an intrepid investigator has stalked the cause of FM in the labyrinth of our neuroendocrine and immune systems. Clues are hard to come by; subtle changes prove unreliable, secondary, or nonspecific. Genetics plays little if any role in an analysis of 11-year old Finnish twins and their families, 10% of whom suffered persistent widespread pain¹⁷. Perhaps heritability will prove different in the Amish cohort White and Thompson propose to study. Other investigators have sought associations with unusual psychological or physical traumatic events but the results are inconsistent at best. Testing biomedical theories is proving difficult but not insurmountable.

Testing a psychosocial or sociocultural theory is far more difficult. I am suggesting that chronic persistent pain is an ideation, a somatization if you will, that some are inclined toward as a response to living life under a pall, and not vice versa. I am not defining “pall” further as my theory countenances a wide range of individual differences in the tendency to somatize. I am further suggesting that these people choose to be patients because they have exhausted their wherewithal to cope. If this is so, the complaint of persistent widespread pain should initiate a treatment act quite different from that leading to labeling as FM. The symptoms of persistent widespread pain should be heard as likely surrogate complaints for psychosocial confounders to coping. Months, often years of poking, testing, pharmaceutical empiricisms, and the iatrogenicity of medicalization¹⁸ might be avoided by directly approaching the challenge to coping. Perhaps the patient can be spared instruction in illness behaviors, and spared contending with contrived neologisms such as “central sensitization.” Then they might not need to attempt to unlearn illness behaviors with “cognitive behavioral therapy” or the like.

For such to eventuate, we would have to witness a dismantling of the social construction represented by FM and the other functional somatic syndrome labels. Then a patient can stand before a Western physician and say, “Doc, I feel awful. Could it be in my mind?” And that physician would reply, “I hope so. That’s a lot better than leukemia, or renal failure, or lupus or the like.” For most Americans, in fact for most Westerners, such repartee is anathema. It is tantamount to an admission that one is feigning, confabulatory, or “crazy.” Most Westerners are offended by the suggestion that their symptoms are in their mind¹⁹.

It is my hope that controversy will work its magic, so that Cartesian mind-body duality will erode²⁰ and the fibromyalgia social construction will be unmasked. Then the person with chronic widespread pain will be afforded succor

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