

Prevention and treatment of “unexplained” syndromes?

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**Some quotations from a Review of Fibromyalgia and related syndromes by
I Hazemeijer and JJ Rasker published in Rheumatology:2003:42:507-515
(134 references)**

Do others agree that this Review by Hazemeijer and Rasker demonstrates the chasm between those who remain embedded in the “biopsychosocial” model of these syndromes and those who prefer to practice the science of 21st century medicine and whose commitment has pushed forward the frontiers of scientific knowledge about these complex disorders?

Mass psychogenic illness; illness as a way of life; hypochondriac beliefs; bodily perception; over-representing of complaints by women: these are all terms which feature in this Review of fibromyalgia by two Dutch authors, from which we learn that for the prevention and treatment of non-legitimate disorders such as fibromyalgia, chronic fatigue syndrome, multiple chemical sensitivity, Gulf War Syndrome and even homosexuality, all that is needed is for the authorities to refuse to allow the existence of the “therapeutic domain” in which such syndromes thrive and these syndromes will disappear. Can this be true, and is this what science and medicine are all about?

The authors looked at the relationship between a specific social setting, which they call the “therapeutic domain”, and the perpetuation of “unexplained” syndromes which they assert cannot be shown by examination or laboratory testing to be “visible disease”.

The authors state that the “therapeutic domain” is where patient and therapist have initiated a relationship, and that this “domain” is influenced by the media and by political pressure. They believe that classification criteria give a “structure to perceptions” which then become “ratified”, and that the patient “constantly has to grow into the conformity of these classification criteria”, which results in a “concept” which becomes manifest in the mind of both patients and doctors, even though there is no such disorder. The authors believe that “labels” turn an “invisible” disorder into a “disease”, and that for the prevention and treatment of these syndromes, doctors as well as politicians and the media have to start by fundamentally changing the “therapeutic domain” so that these syndromes are not permitted to become manifest “and thus can no longer exist”.

The authors state that Wessely’s approach (described as “a firm public message that symptoms can be psychological in origin to prevent their spread”) is only part of the answer to the issue of these “subjective” functional somatic syndromes.

Quotations

“Hadler states that fibromyalgia is a form of illness behaviour escalated in vulnerable patients by labels. However, we hypothesize that fibromyalgia behaviour is facilitated by medical and therapeutic practice”

“This domain constitutes what Hadler calls ‘settings where the hunt for a diagnosis can be harmful to health’ (and is) the social setting in which a particular treatment act plays out, a setting which, in our opinion, has received much too little attention where fibromyalgia and other syndromes are concerned. It has the capacity to generate within its confines a new representation and thus a new syndrome. It is the domain where people can label their internal sensations as illness or disease”

“Syndromes (such as these) are not waiting below the surface until they are discovered by a researcher. On the contrary...in a therapeutic domain a certain power creates reality and hence a form of visible presentation. Most patients labelled as having fibromyalgia have a past medical history that is remarkable for somatization”

“The typical sufferer is a middle-aged person, most often a woman. There are no clinical findings.....then the family doctor decides to perform further blood investigations, but each is normal (but) the information that the patient obtains from glossy magazines, the Internet and friends confirms his or her belief that s/he has fibromyalgia. By this time s/he has become a member of the patient self-help group. Within this therapeutic domain this person has been able to give embodiment to her symptoms.....A so-called looping effect has taken place: the individual and the concept have influenced each other”

“In a different therapeutic domain this person could be diagnosed and classified from a different perspective using other criteria. Fibromyalgia is one of the functional somatic syndromes known by different names by many medical specialists. After referral to a psychiatrist (and) satisfying DSM-IV criteria, s/he could have been classified as having ...psychological factors. Had s/he been referred to the gastroenterologist this person would perhaps have been diagnosed as having irritable bowel syndrome and in the case of referral to the neurologist or internist as having chronic fatigue syndrome”

“Like mass psychogenic illness, fibromyalgia seems to spread through social networks”

“Fibromyalgia occurs in the context of normal examination findings and negative investigation results, resulting in a cascade of diagnostic technology being let loose on the patient.....The patient’s illness behaviour now becomes automatic and perhaps s/he will gloomily enjoy the secondary illness gain”

“People seek medical care generally due to the experience of physical symptoms. However, demonstrable organic cause can be identified for less than 24% of these symptoms. Health care costs of these patients are ten times higher than the average patient. These high utilizers had a mean of eight to nine medically unexplained symptoms over the course of their lives”

“Classifications used as diagnoses are intended to tell clinicians who and how to treat”

“Labelling someone as ‘diseased’ has enormous individual, social (and) financial implications...even non-diseases play a role in the daily practice of every doctor (*here, reference is made the special issue in the BMJ in 2002 on ‘Non-diseases’ and the Editor Richard Smith is quoted*): ‘It is easy to create new diseases and new treatments as many of life’s normal processes, birth, ageing, sexuality, unhappiness and death can be medicalised’ ”

“We agree with Hadler when he quotes Meador by saying that ‘labelling of a non-disease can cause patients to perceive themselves as ill’ ”

“Our hypothesis is that patients shopping around for a diagnostic label that fits them and does not stigmatize them as not being ill is an aspect of ‘the construct fibromyalgia’. We state that only labelling within a certain therapeutic domain will provide them with a socially accepted legitimacy”

“If a description doesn’t exist, then the sufferer cannot intentionally adhere to the described disorder”

“Hadler suggests that it is the doctor who gives direction to the patient’s symptoms...We believe that a therapeutic domain creates their symptoms”

“In the development of fibromyalgia, one is giving credence to making visible something that is not universally present and accepted”

“Fibromyalgia is described as an ‘affective spectrum syndrome’ or as a component of the ‘dysfunctional spectrum syndrome’. This somatization (is) a social accommodation that allows people to express distress passively through physical symptoms (and has) regional dialects, resulting in ‘fashionable diagnoses’ ”

“Women incline more to somatization and pay more attention to physical sensations than men. We agree with Hadler (who stated) ‘The very term, somatization, harkens back to the heyday of psychosomatics, when psychic conflict was thought to be convertible into physical symptoms. Somatization is a stigmatising label; it belittles the symptoms as if they are not real, somehow feigned, perhaps serving some subliminal secondary gain. The American Psychiatric Association categorised fibromyalgia as a ‘somatoform’ disorder (and) a separate category was devised for this spectrum of illness, defined as ‘medically unexplained symptoms and worry about physical illness (which) may constitute culturally shaped ‘idioms of distress’ that are employed to express concerns about a broad range of personal and social problems....’ ”

“Historical examples (include) railway spine, writers’ cramp, epidemic neuromyasthenia, Royal Free epidemic, more recent ‘epidemics’ like the rise and fall of the repetitive strain injury epidemic in Australia, multiple chemical sensitivity, neurasthenia, chronic fatigue

syndrome and perhaps Gulf War syndrome, the multiple personality syndrome and homosexuality”

“We must conclude that a certain therapeutic domain creates a syndrome in a person with non-specific aches and pains with a tendency to somatize and with insufficient coping behaviour”

“There is a dynamic relationship between doctor and patient, between classification criteria and behaviour, laboratory results and symptoms. A result of this looping effect is that when classification criteria give structure to perceptions and are ratified, the person thus diagnosed grows into the conformity of the classification criteria”

“Believers in fibromyalgia as well as sceptics and agnostics will see the same (patients), but the (agnostics) do not allow the sufferer to behave in a fibromyalgia-phenotype way within their (ie. the psychiatrists’) therapeutic domain”

“As Reilly puts it: ‘That the diagnosis of fibromyalgia has gained credibility cannot be doubted...In fibromyalgia, we may have created a monster. Is it now clinically, socially and financially appropriate to slay that monster?’ ”

“The concept of the syndrome has been changed by what we call it”

“Society and medicine have to turn to philosophy rather than to science for the solution of treating and preventing (such) ‘syndromes’. For prevention and treatment (of these syndromes) we have to start by fundamentally changing the therapeutic domain. In such a renewed setting (these syndromes) cannot become manifest in an individual and thus (these syndromes) can no longer exist”.