

Fibromyalgia Over-Diagnosed 97% of The Time: Chronic Pain Due To Thoracic Outlet Syndrome, Acromo-Clavicular Joint Syndrome, Disrupted Disc, Nerve Entrapments, Facet Syndrome and Other Disorders Mistakenly Called Fibromyalgia

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Abstract

A review was conducted of 47 patients referred to Mensana Clinic with the diagnosis of fibromyalgia, and other diagnoses. Of the 47 patients, 9 received only an initial evaluation, and 38 received a partial or complete diagnostic evaluation. The diagnostic criterion for fibromyalgia was not met in 37 of 38 patients. Therefore, 97.3% of patients were misdiagnosed by referring doctors as having fibromyalgia, when they did not meet the diagnostic criteria (errors of commission). Additionally, referring physicians made only 7/50 diagnoses (including fibromyalgia) that were confirmed by objective testing or diagnostic criteria, which means 86 % of the time they made diagnoses that were not confirmed. Referring physicians also failed to diagnose 133 medical conditions that were confirmed by objective testing at Mensana Clinic, for a failure to diagnose rate of 94.3% (errors of omission). Of the patients misdiagnosed with fibromyalgia, i.e. told they had fibromyalgia when they did not, 94.2% of them were women.

Keywords: Fibromyalgia, overdiagnosis, misdiagnosis, chronic pain, expert system.

Introduction

No one physician can hope to understand all the complexities of medicine. For this reason, a variety of specialists, and even sub-specialists have emerged, to try to enhance patient care, and provide a degree of expertise that a generalist cannot possibly hope to achieve. This approach is laudable, because it results in better patient diagnosis and treatment.

Certainly, the field of diagnosing and treating patients with chronic pain is nearly as broad as medicine itself, since pain and injuries are the symptoms that causes a patient to seek medical attention more than others symptoms [1]. As Sir William Osler, the great Johns Hopkins physician of the late 19th and early 20th century said about syphilis, "...it is almost impossible to describe its clinical symptoms without mentioning almost every symptom of every disease known" [2]. Residents at Johns Hopkins Hospital are also taught that Osler was rumored to have said " He who knows syphilis knows medicine," although this quote does not appear in his textbook of medicine [3]. A number of approaches to diagnosis and treatment of chronic patients have emerged. These have ranged from behavioral modification, to providing nerve blocks and epidural electrical stimulation [4]. Obvious, in a field so broad

as chronic pain, a multidisciplinary approach is the only logical way to proceed with diagnosis and treatment [5].

Hendler has published articles indicating that 40% to 67% of chronic pain patients involved in litigation have overlooked diagnoses [6,7]. For certain disorders, such as Complex Regional Pain Syndrome - Type I, (CRPS I) or as it was previously called, reflex sympathetic dystrophy (RSD), the misdiagnosis rate may reach 71% [8].

The diagnosis and treatment of patients who have pain at multiple sites is even more complicated. The American College of Rheumatology 1990 Criteria for the Classification of Fibromyalgia are summarized in Table 1. (<http://www.nfra.net/Diagnostic.htm>, National Fibromyalgia Research Association).

N = 47	
AVERAGE AGE	45.3
Males	3
Females	44
"Post-traumatic Onset (auto accident, lifting, dropped object on foot, after virus, after injection, golf, fall, throwing ball)."	32
Slow, progressive onset (over months)	15

Table 1: Demographics of patients referred with diagnosis of fibromyalgia.

This study was conducted to determine how often a physician rigorously adheres to the diagnostic criteria needed to properly establish a diagnosis of fibromyalgia, and if there are other documented diagnostic considerations in so called “fibromyalgia” patients which may have been overlooked.

Subjects

Charts were reviewed of forty-seven patients who were referred to Mensana Clinic (a multidisciplinary diagnostic and treatment center for chronic pain) with the diagnosis of fibromyalgia during a period from Aug. '00 to Sept. '03. Of the 47 patients who were evaluated, 38 had a partial or complete evaluation at Mensana Clinic. The demographics of the patient population are show in Table 1. There were 3 male and 44 female patients, from 5 states.

Methods

Consecutive referrals to Mensana Clinic with the original diagnosis of fibromyalgia were included in this study. A review was conducted of the complete medical chart prior to referral to Mensana Clinic, including laboratory results, and clinical reports from treating and consulting physicians. Other diagnoses, in addition to fibromyalgia, made by the referring or treating physicians, were also recorded. A blind review of the charts was conducted by one of the authors (TR), who has served as a member of the committee of the American Rheumatologic Society, which developed the diagnostic criteria for fibromyalgia. He determined if the location of the patients complaints, laboratory tests, and physical examination were compatible with the diagnosis of fibromyalgia.

As part of the Mensana Clinic program, all patients were evaluated by the clinical director, for at least one hour, and 38 of the 47 patients received additional diagnostic studies and laboratory tests done at area hospitals or radiology groups. Nine of the 47 patients received only an initial evaluation, due either to the fact they did not have adequate insurance coverage to pursue a multidisciplinary evaluation, or they did not wish to return. They were excluded from the study. Of the remaining 38 patients, 18/38 had only a partial evaluation, (defined as some recommended, but not all recommended, objective testing was performed) and 20/38 had a complete multidisciplinary evaluation (defined as all recommended objective testing was performed). Only patients with partial or completed evaluations are included in this study. Depending on the patient’s symptoms objective testing included flexion extension X-rays of the spine, Doppler flow studies, MRI of the spine, 3D-CT of the spine, bone scan, electromyography (EMG, nerve conduction velocity studies (NCV), neurometer studies (current perception threshold), root blocks, facet blocks, nerve blocks, sympathetic blocks, provocative discograms, blood studies, PET of the brain, SPECT of the brain, EEG, MRI of the brain, and neuropsychological testing. After testing was completed, the patients also received evaluations for their complaints, with various medical specialists, who are on the faculty of Johns Hopkins University School of Medical or University of Maryland School of Medicine. With the exception of neurometer testing, Mensana Clinic received no financial gain from testing nor referrals.

To evaluate the findings from the laboratory testing in a clinically consistent manner, abnormalities were tabulated and categorized as 1) none present, 2) mild or 3) moderate to severe (Table 2) based on quantitative and qualitative interpretations, which follow.

Study	Number of Patients Tested	None	Abnormality Mild	Moderate/severe	Percent Abnormal
EMG/NCV	7	1	2	4	85%
Neurometers	28	0	8	20	100%
3D-CT	15	2	2	11	86%
Root block	4	0	0	4	100%
Facet block	3	0	0	3	100%
Doppler Flow	4	0	0	4	100%
Provocative Discogram	6	0	0	6	100%
MRI	25	2	5	18	92%
Nerve Block	3	0	0	3	100%
Neuropsych Testing	0	0	0	0	0
PET of Brain	2	2	0	0	0
SPECT of Brain	2	1	0	1	50%
Bone Scan	1	0	0	1	100%
Gallium	1	0	0	1	100%
Blood Studies	20	3	0	17	85%
DEXA	1	0	1	0	100%
Total Number of Tests	122	11	18	93	91%

Table 2: Distribution of Test Results Based on Severity of Abnormality for Patients Diagnosed with Fibromyalgia partial or complete evals N = 38 of the original 47 evaluation of tests ordered, 91% of the time an abnormality was found, that substantiated a disease other than fibromyalgia.

Laboratory results were assessed by the senior author, without the name of the patient, or admitting diagnosis being known. Specific criteria for inclusion in a particular category for each test were codified, as follows: An MRI of the cervical or lumbar spine was considered mildly abnormal if there was a small central disc herniation, moderately abnormal if the report indicated frank disc herniation, and severely abnormal if the report mentioned root compression, cord compression and/or spinal stenosis. Bulging discs, spondylosis, degenerative discs and reduced disc space height were not considered abnormal. Provocative discograms were considered moderately abnormal only if the patient experienced pain concordant with the anatomical distribution of pain they normally experienced, at the time of the provocation, with a rating of 5/10 or 6/10 for their pain. Ratings of 7/10 or greater were considered severely abnormal. Doppler studies of the arms were considered moderately abnormal only if there was reduction of pulse wave amplitude of 30% to 50% with Roos maneuver or 180 degrees of abduction, and severely abnormal if the reduction was 51% or greater. Neural foraminal stenosis was graded based

on the radiologist's report of mild, moderate or severe findings on 3D-CT and/or MRI. Neurometer results were considered abnormal based on previously published criteria for abnormality [9]. Electromyographic (EMG) and nerve conduction velocity (NCV) abnormalities were graded according to the reports from the physiatrist or neurologist performing the test. Root blocks, nerve blocks and facet blocks were graded on a comparison of pain reduction, between pre-block and post block pain, using a subjective 0-10 pain rating scale. The severity of abnormality of the PET scan and/or SPECT of the brain was based severity noted on report from the radiologist.

Diagnoses were given to each patient at four stages in their treatment: 1) Referral Diagnoses, that they had prior to being seen at Mensana Clinic 2) Preliminary Diagnoses after the initial evaluation with the clinical director of Mensana Clinic, 3) Intermediate Diagnoses, made after the initiation of the diagnostic evaluation, but before all diagnostic studies and consultations were completed, and 4) Final Diagnoses after a complete multidisciplinary evaluation at Mensana Clinic.

Table 3 shows the distribution of the diagnoses most commonly used by referring physicians, and whether or not Mensana Clinic confirmed that diagnosis after an intermediate and/or complete diagnostic evaluation. Table 4 shows the most common diagnoses established by Mensana Clinic, documented by abnormal objective testing (not a clinical diagnosis), after a partial or full diagnostic evaluation was conducted at Mensana Clinic, and indicates if this diagnosis was mentioned by the referring physician. Thus, Table

3 represents diagnoses typically used by referring physicians, and Table 4 represents diagnoses that are typically overlooked by referring physicians.

N = 38 Diagnosis	Cases at Referral*	Referral Diagnoses Confirmed By mensana clinic
Fibromyalgia	38	1
Sjogren's	1	1
Rheumatoid arthritis	2	1
Osteoarthritis	1	1
Lymes	1	1
Migraine	1	0
Cervical Facet Syndrome C2-7	1	1
Reflex sympathetic dystrophy	4	0
Acromo-clavicular joint impingement	1	1
Total*	50	7

Table 3: fibromyalgia and other diagnoses used by referring doctors, Compared to diagnoses confirmed at mensana clinic.

(*some patients had multiple diagnoses), Number of diagnoses made by referring physicians that were confirmed 7; Number of diagnoses made by referring physicians that were not confirmed 43/50 (86%); Number of diagnoses of fibromyalgia that were unconfirmed 37/38 (97.3%).

	Number of Patients Diagnosed by Referring Physicians	Number of Patients Diagnosed by Mensana Clinic*	Diagnosis Made by Referring Physician	Diagnosis Missed by Referring Physician Made by Mensana Clinic
Fibromyalgia	38	1	37	0
Reflex Sympathetic Dystrophy (n)	4	0	4	0
Sjogren's (m)	1	2	0	1
Rheumatoid arthritis (m)	2	1	1	0
Osteoarthritis	1	2	0	1
Lymes (m)	1	3	0	2
Lupus (m)	0	3	0	3
Diabetes (m)	0	3	0	3
Migraine	1	0	1	0
Post-mono-nucleosis syndrome (m)	0	1	0	1
Tietze syndrome	0	3	0	3
Rib Tip Syndrome	0	3	0	3
Post-Concussion Syndrome (a)	0	1	0	1
Pericarditis	0	1	0	1
Hypothyroidism (m)	0	2	0	2
Hyperthyroidism (m)	0	1	0	1
Hashimoto's thyroiditis (m)	0	1	0	1
Hypoparathyroidism (m)	0	2	0	2
Ankylosis Spondylitis (m)	0	2	0	2

Thoracic Outlet Syndrome (e)	0	15	0	15
Cervical Radiculopathy (d)	0	3	0	3
Cervical Facet Syndrome C2-7 (e)	1	2	0	1
Disrupted Cervical Disc (f)	0	9	0	9
Unstable Cervical Spine (anteriolysthesis)	0	2	0	2
Temporal Mandibular Joint Syndrome (g)	0	7	0	7
Cervical Neural Foraminal Stenosis (i)	0	4	0	4
Ulnar nerve damage (j)	0	9	0	9
Median nerve damage (j)	0	2	0	2
Torn Ligament ankle (k)	0	1	0	1
Abdominal Adhesions (k)	0	1	0	1
ilio-hypogastric N entrapment (j)	0	1	0	1
Acromo-clavicular joint impingement (k)	1	13	0	12
Glenoid labral or subscapularis tear tear (k)	0	4	0	4
Supraspinatus or bicipital tendonitis (k)	0	7	0	7
Peroneal nerve damage (j)	0	3	0	3
Tibial nerve entrapment (j)	0	1	0	1
Sciatic nerve damage (j)	0	1	0	1
Piriformis Syndrome (j)	0	1	0	1
Lateral Femoral Cutaneous nerve damage (j)	0	1	0	1
Disrupted Lumbar Disc (f)	0	5	0	5
Lumbar Facet Syndrome L3-S1 (e)	0	6	0	6
Lumbar Neural Foraminal Stenosis (i)	0	1	0	1
Lumbar Radiculopathy (d)	0	1	0	1
Lumbar or Cervical Spinal Stenosis (l)	0	1	0	1
Vasculitis	0	1	0	1
Cerebral Palsy	0	1	0	1
spina bifida occulta	0	1	0	1
Thalamic aneurysm	0	1	0	1
Peripheral Neuropathy	0	1	0	1
Anemia	0	1	0	1
Coccydynia	0	1	0	1
TOTAL DIAGNOSES	50	140	43	133

Table 4: The most common diagnoses in patients diagnosed as fibromyalgia by the referring physicians but having other diagnoses, confirmed by objective testing at mensana clinic. N = 38 partially completed or completed evaluations (of 47 patients seen with referral diagnoses of fibromyalgia, and other disorders).

Tests used to confirm diagnoses:

(a) PET, SPECT and/or neuropsychological tests, (b) EEG and/or positive clinical response to anti-convulsants, (c) Dopplers and/or EMG/NCV, (d) EMG/NCV and/or root block, (e) 3D-CT, MRI and/or facet block, (f) MRI, 3D-CT and/or provocative discogram, (g) cine MRI, (h) ENG and/or BAER, (i) Flex-Ex X-ray, 3D-CT and/or MRI, (j) neurometer, EMG/NCV and/or nerve block, (k) MRI, (l) MRI and/or 3D-CT, (m) blood studies, (n) bone scan and/or sympathetic blocks, (o) bone scan, sympathetic blocks, and/or nerve blocks, (p) MRI, (q) MRI, 3D-CT, and/or root block.

Number of correct diagnoses made by referring physicians was 7 (Table 3).

Incorrect diagnosis rate for fibromyalgia was 37/38 or 97.3 % (error of commission)

Overall incorrect diagnosis rate was 43/50 or 86 % (error of commission)

Overall failure to diagnosis rate was 133/140 or 95 % (error of omission)

*all 38 patients had multiple diagnoses.

Using the criteria above, the results were biased against abnormalities being found in this group of patients, since a) 18 of the 38 patients did not have a completed diagnostic evaluation at the time of this article, and b) inclusion criteria for a test to be considered abnormal were purposely narrow. Laboratory results were interpreted as normal if there were no findings reported by outside physicians, or if there were minimal results reported, such as a disc bulge or spondylosis on MRI, CT or x-ray studies, without neural foramina stenosis, lateral recess stenosis nor spinal stenosis, minor arthritic changes on bone scan, relief less than 60% after nerve blocks, root blocks, or facet blocks, and pain provocation that was not concordant with the patient's symptoms, and less than 6/10 on provocative discogram.

For the purposes of this article, a patient was considered to have a missed diagnosis if:

- The referring physical had made a diagnosis that was descriptive (low back pain), and not a diagnosis at all,
- The referring physician made a diagnosis of fibromyalgia that did not meet the diagnostic criteria for this disorder.
- The referring physician made a diagnosis that was not supported by objective anatomical or physiological testing later done at Mensana Clinic (having a referral diagnosis of RSD, but having negative bone scan, and no pain relief for even one hour, after a properly performed sympathetic block).

For the purposes of this article, a patient was considered to have an overlooked diagnosis if:

- Mensana Clinic established a diagnosis, not previously mentioned by the referring physician, and confirmed the diagnosis by objective testing at Mensana Clinic (such as no mention of tibial nerve entrapment by the referring physician, and having the diagnosis made during the Mensana Clinic evaluation, and confirmed by EMG/nerve conduction velocity testing and at least one hour of pain relief after a tibial nerve block).

Results

Of the 47 patients initially evaluated, 38 patients had a partial or complete multidisciplinary evaluation at Mensana Clinic. As the result of the diagnoses obtained at the time of the initial evaluation, a variety of diagnostic studies were ordered.

The results of these diagnostic studies are shown in Table 2. Of the 38 patients with partial or complete evaluations, 122 laboratory tests were conducted. Mild abnormalities were found on testing in 18/122 tests, and moderate to severe abnormalities were found in 93/122 tests. The diagnostic criterion for fibromyalgia was not met in 37 of 38 patients, as the result of finding an explanation for the source of pain. Therefore, 97.3% were misdiagnosed by referring doctors as having fibromyalgia, when they did not have it (errors of commission). Of all 122 tests ordered for these 38 patients, 90.9 % were mildly, moderately or severely abnormal, and confirmed the original clinical diagnosis of the clinical director of Mensana Clinic 93 % of the time.

Table 3 shows the diagnoses used by referring physicians for their patients diagnosed with fibromyalgia and other disorders. Of the 50 diagnoses made by referring physicians in 38 patients, only 7 were later confirmed by Mensana Clinic. In this instance, the referring physician made unsubstantiated diagnoses 86 % of the time (error of commission).

Table 4 lists 140 confirmed diagnoses established by Mensana Clinic in the 38 patients originally diagnosed with fibromyalgia and other disorders by referring physicians. Only 7 diagnoses, made by referring physicians, were later substantiated by Mensana Clinic. Referring physicians did not mention 133 diagnoses, which were later confirmed by Mensana Clinic. Based on these findings, the overlooked diagnosis rate for so called "fibromyalgia" patients was 94.3 % (error of omission).

Several concepts can be derived from this research, and are supported by articles in the literature. One major factor of fibromyalgia is the pain that patients experience. Chronic pain patients get depressed as the result of their chronic pain [10]. Depression occurs in 77% of patients with chronic pain, and 89% of these patients had never been depressed before the onset of their pain [11]. The severity of pain specifically associated with fibromyalgia also produced depression [12]. The depression may last from three to twelve years after the onset of pain [13]. This has dire consequences. Fishbain and his colleagues report that the completed suicide rate amongst white male chronic pain patients is two times higher than the general population, and for white females, it is one and an half times higher than the general population. However, more startling is the suicide rate for white males involved in workers compensation litigation, where the completed suicide rate jumps to 3 times higher than the general population [14].

In addition to the psychological factors associated with pain, there are neuropsychological issues, sociological and legal concerns as well as financial issues, and return to work problems. The need to increase functioning, despite the use of narcotic medication, drug diversion, cognitive impairment from medication, the residua from the injury or the use of medication, religious issues and others, all make up the complex picture of a chronic pain patient [15].

It is very hard to objectively quantify the symptoms of fibromyalgia, even though there have been various attempts, using tenderness of the pressure points, thyroid hormone, post-traumatic etiology, hyper-mobility of joints, and neuroticism [16-22].

Moreover, there has been the realization that there is still a need for precision in applying the diagnostic criteria for fibromyalgia, ten years after the criteria had been established [23]. This is further complicated by the great overlap between symptoms of fibromyalgia and other disorders, such as Lyme disease, systemic lupus erythematosus (SLE), and Raynaud's phenomenon, resulting in patients with unconfirmed symptoms of these disorders being labeled as fibromyalgia. Additionally, other authors have recognized the overlap in symptoms between fibromyalgia carpal

tunnel [24-30]. These articles reported many patients mistakenly diagnosed with fibromyalgia were correctly diagnosed with carpal tunnel, which is compatible with the findings of this article [29-30].

Additionally, this article show that disc disruptions occur in a significant number of patients mistakenly diagnosed with fibromyalgia. The mechanisms for the source of pain from internal disc disruption, which escapes detection on MRI 78% of the time, have been well described [31,32]. Essentially, the nucleus pulposa herniates into the posterior portion of the annulus (disc), where pain fibers are located [32]. However, there is no anatomical disruption of the disc, so the disc appear normal on MRI but produces the same clinical features of a herniated disc where the nucleus pulposa compress the nerve root or spinal cord, with associated neck, back or limb pain, and severe muscle contractions [31,32].

In order to assist physicians establish the correct diagnoses, and to avoid both errors of omission and commission, a number of so called “expert systems” have been developed. The accuracy of any computer scored and interpreted expert systems is a major issue. Those expert systems that seem to have the best results are the ones that focus on a narrow and highly specialized area of medicine. One questionnaire, consists of 60 questions, to cover 32 rheumatologic diseases, for 358 patients [33]. The correlation rate was 74.4%, and an error rate of 25.6%, with the 44% of the errors attributed to “information deficits of the computer using standardized questions,” but in a later version “RHEUMA” was studied prospectively in 51 outpatients, and achieved a 90% correlation with clinical experts [33,34]. Several groups have approached the diagnosis of jaundice. ICTERUS produced a 70% accuracy rate, while ‘Jaundice’ also had a 70% overall accuracy rate [35,36]. An expert system for vertigo was reported, and it generated and accuracy rate of 65% [37]. This later was reported as OtoNeurological Expert (ONE), which generated the exact same results reported in the earlier article [38]. A group of physicians from Johns Hopkins Hospital developed an “expert system” which specifically addressed 104 of the most common chronic pain problems, including fibromyalgia. This test gives diagnoses with a 96% correlation with diagnoses of Johns Hopkins Hospital staff members, and can be found at www.DiagnoseMyPain.com [39]. The questionnaire is available in English, Spanish, Portuguese, French, Italian, German, Russian, and Arabic, or in English and Spanish at www.MarylandClinicalDiagnostics.com.

In summary, fibromyalgia may have become the “disease de jour” for the medical community. The absence of strict adherence to the diagnostic criteria for diagnosing fibromyalgia has led to many missed diagnoses [23]. The data presented in this paper support the concept that more rigorous application of the diagnostic criteria for fibromyalgia is needed by the medical community. Moreover, there are many medical problems which have some of the symptoms of fibromyalgia, but each symptom may have multiple etiologies and needs to be examined independently, to avoid overlooked or missed diagnoses.

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