

# Should Rheumatologists Retain Ownership of Fibromyalgia?



## THE FIBROMYALGIA QUANDARY OF THE LAST 2 DECADES

Fibromyalgia (FM) has courted controversy since formal recognition in the mid-1980s<sup>1-4</sup>. Ambivalence regarding the very existence of this condition has at times stimulated heated debate. As FM was initially believed to be a rheumatic complaint due to the presence of body pain and soft tissue tenderness, rheumatologists, by default, have had responsibility for the diagnosis and, often, continued management of these patients. This ownership was consolidated by the development of criteria for diagnosis of FM by the American College of Rheumatology (ACR) in 1990<sup>5</sup>.

Over the last 2 decades there has been an evolution in the understanding and awareness of FM, which may affect between 2% and 4% of the population<sup>6-8</sup>. The scientific basis for FM is now firmly grounded with objective neurophysiologic evidence. FM can no longer be categorized as a rheumatic disease process, but rather is a pain syndrome centered in the nervous system<sup>9-12</sup>. It is also increasingly clear that optimal management of patients with FM requires the healthcare team to address a broad spectrum of varied complaints that go beyond a simple complaint of pain<sup>13</sup>. We therefore propose that now is the time for rheumatologists to reevaluate their responsibility for both the diagnosis and care of patients with FM.

## PRIMARY CARE PHYSICIANS DEMONSTRATE IMPROVED DIAGNOSIS OF FM

This call for change for the care of FM patients seems even more plausible in light of the report by Shleyfer and colleagues in a recent issue of *The Journal*<sup>14</sup>. The authors have shown that family physicians can correctly diagnose FM in 70% of patients, and of particular note, other important medical conditions were not missed. This shows considerable improvement from the less satisfactory appreciation of FM by family physicians reported by this same group 10 years ago<sup>15</sup>. Their new study is noteworthy from 2 aspects: first, the referring physicians in their current report were

almost as good as the specialist rheumatologist in correctly identifying FM, and second, and most reassuring, other diseases such as treatable rheumatic diseases were not missed in those with another diagnosis.

In the early 1990s, following formal recognition of FM, there was a trend to assign FM diagnosis too freely to women, in particular those presenting with musculoskeletal pain; this resulted in overdiagnosis as well as misdiagnosis<sup>16,17</sup>. Some authors report that up to 11% of individuals in population studies may be affected by chronic widespread pain, which would account for a large burden of suffering<sup>18</sup>. Indeed, we have previously reported that referring physicians ascribed an incorrect diagnosis of FM in two-thirds of patients referred for rheumatology consultation and misdiagnosed inflammatory rheumatic diseases such as FM<sup>17</sup>. The current report shows considerable improvement compared to the poor accuracy identified over the past decade. This improved accuracy in the diagnosis by family physicians sets the stage for reconsideration of the optimum healthcare pathway for patients with FM.

The exact diagnoses in the 30% of patients incorrectly given a diagnosis of FM by referring physicians require comment<sup>14</sup>. The most common condition to be mislabeled as FM was arthralgia. Arthralgia may evolve into a true arthritic disease, resolve completely, or conceivably manifest a chronic pain syndrome. Irrespective of the outcome for patients diagnosed with arthralgia, no treatment other than symptomatic relief at the time of diagnosis would be indicated. Thus, this incorrect diagnosis is of lesser concern than a missed diagnosis of a true inflammatory rheumatic condition, or other medical illness requiring specific treatment. These include among others hypothyroidism, statin-induced myopathy, and polymyalgia rheumatica, conditions that are familiar to primary care physicians and should not cause confusion.

It is also possible that a diffuse pain syndrome may herald the early stages of either some treatable rheumatologic condition such as rheumatoid arthritis or systemic lupus

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See Accuracy of diagnosis of FM by family physicians, page 170, January 2009 issue

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erythematosus, or a neurological illness such as multiple sclerosis. Patients in the current study were followed for a period of 6 months without any report of change in diagnosis, once again providing reassurance regarding missing some other important disease. There is probably therefore only a minority of patients with the symptom of chronic widespread pain who truly require specialist evaluation. Conversely, mislabeling a patient with an incorrect diagnosis of FM may also have negative consequences with regard to physical and mental well-being. Unfortunately, to date, the gold standard for diagnosis of FM is simply “the blessing” of the rheumatologist, a practice that is not infallible.

### ACCEPTANCE OF THE CONCEPT OF FM

It was with reservation that the medical community gradually accepted FM as a true illness. Some have even vigorously advocated against the validity of patient report of complaint without objective physical findings<sup>2,3</sup>. The recognition that pain may be present in the absence of measurable clinical abnormality is now fully supported by objective neurophysiological study<sup>19</sup>. Abnormalities have been identified at various levels in the peripheral, central, and sympathetic nervous systems, as well as the hypothalamo-pituitary-adrenal axis stress-response system<sup>20-25</sup>.

Unfortunately, to date, there is no single diagnostic test that can be performed in the clinical setting to validate a diagnosis of FM. Even so, the clinical awareness of FM has continued to increase, with publications spanning numerous medical disciplines and with emphasis on a positive clinical diagnosis without the need for extensive and unnecessary investigations<sup>13</sup>. Indeed a positive diagnosis of FM is associated with reduced healthcare utilization and reduction in investigations<sup>26</sup>. No longer should FM be a diagnosis of exclusion.

The impressive progress in understanding pathogenic mechanisms of FM has, however, not seen a parallel in the clinical arena. This condition continues to present challenges to the clinician from a number of perspectives, including total reliance on subjective patient report of symptoms, absence of an objective test to confirm or refute the complaint, and generally imperfect response to treatments. Although treatment options for FM are increasing, the numerous symptoms associated with this syndrome emphasize the importance of nuances required to effectively manage these patients.

### OPTIMAL PATIENT TRAJECTORY

Ideal care of patients with FM in the first instance requires a correct diagnosis, and thereafter, appropriate management. FM is an illness that is highly dependent upon the art of medicine and communication with the patient, qualities that epitomize good primary medical care. There has been repeated emphasis by numerous bodies and authors to curb unnecessary investigation, as well as over-medicalization of

patients presenting with diffuse pain<sup>26-29</sup>. A confident diagnosis can thus be made with use of good clinical skills that combine careful medical history and physical examination, and use of only focused investigations if indicated. Indeed, the American Pain Society currently recommends only minimal laboratory testing to exclude some other diagnosis<sup>27</sup>, which suffices for the majority of patients. These requirements are all completely within the domain of the primary care physician and do not require specialist input. Unnecessary investigations and consultations will have negative consequences by reinforcing uncertainty in the diagnosis and accentuating the sickness role for these patients.

Almost all patients with FM will have a symptom complex characterized by presence of at least 4 major complaints of variable intensity: pain, sleep disturbance, fatigue, and mood disturbance<sup>28</sup>. Additional symptoms commonly associated with chronic widespread pain include abdominal complaints, chronic headaches, cognitive changes, and hypersensitivity phenomena. To date, there is no single treatment intervention that successfully addresses all these issues concomitantly. The management of patients with FM is therefore increasingly multifaceted, with a move away from reliance on traditional simple pharmacologic measures, and evidence supporting the use of pain management strategies such as cognitive behavioral training, relaxation, meditation, massage, and others, many of which are unfamiliar to routine rheumatology practice<sup>13,30-33</sup>. Indeed, even the pharmacologic treatment options for patients with FM are rapidly expanding with the increasing use of adjuvant medications, including antidepressants and antiepileptic drugs<sup>34-36</sup>. Successful management necessitates approaching the patient as a whole biopsychosocial being, with treatment strategies directed towards physical and psychological complaints within the context of family and society.

### A PROPOSED CHANGE FOR CARE OF PATIENTS WITH FM

In the ideal world, patients with FM would be best managed in a multidisciplinary healthcare setting with healthcare professionals of various disciplines contributing to care as needed<sup>32,33</sup>. The perfect world does not exist and therefore only a small proportion of patients with FM are likely to be treated in this ideal setting. What then might be the most realistic, but also effective solution? Although any physician may glibly prescribe a treatment that is less familiar, best medical practice urges that the healthcare provider be thoroughly knowledgeable of these recommendations. The multiple and varied treatment strategies clearly move FM out of the rheumatology domain.

We propose that primary care physicians are today the most appropriate and best qualified physicians to manage these patients. Other healthcare professionals such as neurologists, psychiatrists, or psychologists may be equally capable of managing patients with FM, but again, resources

are limited and would likely preclude continued care and followup.

The time is ripe for rheumatologists to consider abrogating care of these patients for these reasons: the pathogenesis of FM is now firmly centered in the nervous system, and FM is not a musculoskeletal complaint. Optimal patient management requires attention to the many symptom components of FM in addition to pain management. Patients with FM will also require prolonged care with continued tailoring of treatments, as symptoms are likely to change over time. Finally, as 2% to 4% of the population suffers from FM, it would be unrealistic to require that all or most of these patients be evaluated or followed by rheumatologists.

A heightened awareness of FM in the past decade has been practically translated into improved recognition of FM by family physicians in Israel. We hope that this improvement exists in other countries, but it still requires verification. With a definite move away from a musculoskeletal focused process, patients with FM should no longer require rheumatologic evaluation and there should be a shift of responsibility for both diagnosis and care of patients into the primary care setting. Energy should now be directed to ensure adequate education for treating physicians regarding differential diagnosis of diffuse pain syndromes, awareness of confounding conditions, and appreciation of treatment options, which should be tailored to individual patient needs.

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