

# Stop Using the American College of Rheumatology Criteria in the Clinic



The study of fibromyalgia (FM) in an Amish community by White and Thompson raises some issues of importance<sup>1</sup>. They found that 7.3% of persons in the Amish community satisfied their tender point based criteria for FM. They concluded that FM is relatively common among the Amish. By contrast, our 1995 US study in the general population found rates of FM to be about 2%<sup>2</sup>. The White and Thompson study tells us about tender points but very little about the persons who have these tender points, and little about what they mean. Perhaps there have now been enough studies of FM prevalence using the American College of Rheumatology (ACR) criteria<sup>3</sup>. Perhaps it is time to rethink the role and value of the ACR criteria.

## WHAT'S WRONG WITH FM AND THE ACR CRITERIA?

FM arose in the late 1970s and early 1980s because of a need to better characterize and understand patients with pain. Almost all rheumatology illness was then described in mechanistic, immunological, or anatomic terms. The idea that fatigue, sleep disturbance, and pain alone could represent illness was new to rheumatology, as was the idea of what is referred to in the breach as the bio-psychosocial model of illness. FM was fought bitterly in those days by the same persons who now compete for the US National Institutes of Health (NIH) grants to study it and build centers for its treatment. The ACR criteria that were developed in the next decade were a sensible attempt to provide a working tool for studying this diffuse and hard to characterize syndrome. As criteria, they worked well, but they ignited the FM wars that, even now, continue to rage.

## TENDER POINTS

Perhaps tender points, as the essential criterion, was a mistake. By ignoring the central psychosocial and distress features of the syndrome and choosing instead a physical examination item, we allowed FM to be seen as mostly a physical illness. More than that, we removed all traces of the most central features of the illness. It was OK science, but it was bad reality.

## THE IMPLICATION OF SEVERITY

The ACR criteria defined FM in a way unique to rheumatic disease criteria. Instead of defining illness by its features, the ACR criteria defined FM by severity of symptoms. Widespread pain and generalized tenderness: what could be worse? It is as if we were to define rheumatoid arthritis (RA) by requiring 25 swollen joints, or diabetes by requiring diabetic coma. By defining pain and distress in this special way, we opened the door to the *prima facie* claim of disability.

In addition, by placing diagnosis at the end of the severity spectrum we lost the appreciation of the spectrum itself, of the range of human distress that exists across all illness and persons, not just in those with 11 tender points. Figure 1 shows the distribution of a combined variable in 15,997 RA patients and 1,767 with FM diagnosis registered in the National Data Bank for Rheumatic Diseases. The variable, based on principal component analysis, is an optimum combination of fatigue, the regional pain score<sup>4</sup>, a count of somatic symptoms, and a count of lifetime comorbid illnesses. Seventy-five percent of patients with FM have scores of 39 or greater (the point where the curves cross), as do 29% of patients with RA. If we just look at the RA curve, as it is representative of FM-related symptoms, it should be clear that such FM-related symptoms are present in RA, as they would be in other illnesses. Such symptoms are distributed broadly across rheumatic and nonrheumatic illnesses of all types. We do patients a disservice if we ignore such data and only look for and see the FM extreme.

## DO WE NEED THE ACR CRITERIA?

Assuming equal numbers of FM and RA patients in each group, the symptoms listed above have a classification accuracy of 74%. However, there is considerable misclassification present, as more than 20% of RA patients also have FM and 20% of those classified as having FM have few FM symptoms. Adjusted for misclassification, the classification accuracy of the symptom complex is approximately 84%.

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

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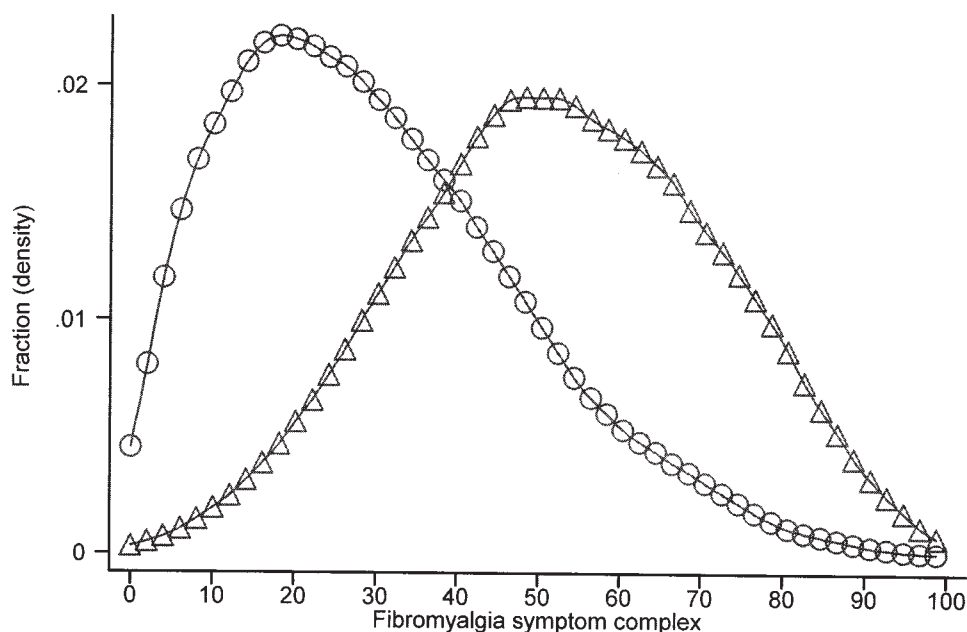


Figure 1. Distribution curves of a composite variable formed by principal component analysis. The variable represents an optimum combination of fatigue, the regional pain score<sup>4</sup>, a count of somatic symptoms, and a count of lifetime comorbid conditions. The curve to the right represents persons diagnosed with FM (N = 1,767) participating in the National Data Bank for Rheumatic Diseases (NDB), and the curve on the left represents RA patients in the NDB (N = 15,997). The curves and symptoms clearly overlap. The best point of separation is at 40.

This means that it is really possible to identify FM-like illness without tender points. It also means that symptoms can tell us much about all patients without the use of the tender point examination and the ACR criteria.

The White and Thompson study<sup>1</sup>, finding increased rates of FM in the Amish, was undertaken for a political reason, to show that FM could be found in settings where litigation does not occur. However, it illustrates instead the central problem of FM, i.e., that diagnosis has become a social and political issue. It also may remind us that palpating patients in open studies where the goal is to make a political point is not good science and may make just the opposite point. That White and Thompson can find 7.3% with FM and we find only 2.0% speaks more to the reliability of the examinations than of true difference. The harder you press (the more you believe?), the more FM you find. Whether one believes in FM or not, tender points capture neither the distress of FM, nor the pain, nor the myriad accompanying symptoms. Perhaps to deal with FM more realistically, it is time to deal with the symptoms rather than the disease-creating tender points.

### CHE FARE?

The NIH and the Arthritis Foundation see the world in a fibromyalgia dichotomy. *What can we do?*<sup>5</sup> The lawyers and disability agencies think tender points equate with disability. *What can we do?* Rheumatologists can help restore sense to the world. Record and understand the suffering and symptoms of patients; try to help. But let us stop using the ACR criteria in the clinic and let's stop using

them in medical reports. The London group is a well known and respected research group, but should there be more studies of the type they are reporting here? I hope not. In clinical rheumatology, the dominant NIH model of proving what is already known and unimportant has not served us well.

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