

# Awareness and perceptions of fibromyalgia syndrome: a survey of Malaysian and Singaporean rheumatologists

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## ABSTRACT

**Introduction:** Fibromyalgia syndrome (FMS) is a common but controversial condition. There appears to be different levels of belief of its existence and awareness. We set out to explore the variations of perceptions and awareness of this condition among rheumatologists from Malaysia and Singapore.

**Methods:** 48 rheumatologists from Malaysia (28) and Singapore (20) were approached to participate in this survey by answering a specific questionnaire regarding their belief in FMS. 23 respondents from Malaysia and 20 from Singapore completed the questionnaire.

**Results:** 91 percent of Malaysian rheumatologists and 95 percent of the Singaporean believe that FMS is a distinct clinical entity and that this condition is considered an illness rather than a disease. 87 percent and 90 percent of rheumatologists from Malaysia and Singapore, respectively, believe that FMS is a mixture of medical and psychological illness. However, not many of those in the university setting include FMS in their undergraduate teaching. 87 percent and 80 percent of the respondents from Malaysia and Singapore, respectively, also ordered blood tests to exclude other serious pathologies, and 100 percent of the respondents from both countries also prescribed some form of drugs to their FMS patients.

**Conclusion:** This study confirmed that there was a variation of perceptions and knowledge of FMS among rheumatologists

from Malaysia and Singapore. The majority of rheumatologists recognise that FMS is a distinct clinical entity, and is diagnosed by excluding other well-defined clinical diseases through a combination of clinical evaluation and screening tests.

**Keywords:** fibromyalgia syndrome, musculoskeletal disease, rheumatological disease, rheumatologist survey

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## INTRODUCTION

Fibromyalgia syndrome (FMS) is common syndrome of diffuse aching, pain or stiffness in the muscles or joints, accompanied by tenderness on examination at specific and predictable anatomical sites known as tender points<sup>(1)</sup>. It affects 3% of the general population, and is now recognised as a common clinical entity in many countries. The prevalence of FMS varies significantly in reports from various countries. In the western countries, such as the United States (US), three to six million people may be afflicted with FMS, while in Mexico, Spain and Australia, a high prevalence of FMS has been reported, ranging from 10.2% to 14.9%<sup>(2)</sup>. FMS has been reported in 13%–20% of rheumatology practice, 5%–7% of internal medicine settings, and 2% of younger patients within a family practice<sup>(3–7)</sup>.

Despite intensive research of the pathogenesis and pathophysiology of FMS, major gaps in our understanding of its aetiology still remain. No distinctive tissue pathology or psychopathology has been found. It is a highly perplexing and controversial disorder as it does not fit the traditional biomedical model of illness where diseases are considered either to be physical or psychological<sup>(8)</sup>. In 1990, the American College of Rheumatology (ACR) published criteria for the classification of FMS<sup>(9)</sup> at a large multicentre study, intended to identify classification (diagnostic) criteria for the syndrome. According to this set of criteria<sup>(9)</sup>, fibromyalgia is a syndrome of widespread pain, by definition affecting both sides of the body and

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the upper and lower segments. Its symptoms may also include sleep disturbance, fatigue, and stiffness. The most important feature is, however, the "tender point" count. Most of the studies, led particularly by Bennett et al<sup>(10)</sup>, Yunus et al<sup>(7)</sup>, and Wolfe et al<sup>(9)</sup>, showed that these tender points are invariably present in FMS patients, and that they can be used to distinguish FMS from other painful joint and muscle diseases.

The prevalence of FMS in our region is not known and is almost unheard of. It is understandable that musculoskeletal complaints comprise a quarter of the general practitioner's patient's presentation but only a few of these patients were diagnosed as having FMS<sup>(5)</sup>. The reason for the apparently low diagnosis rate is the fact that family and primary care physicians are unfamiliar with FMS or unable to recognise the symptoms. The early recognition of FMS is important, as it will prevent costly and unnecessary tests, and will avoid delay in making the diagnosis and starting treatment. The main objective of this survey is to explore the variations in perceptions, knowledge and awareness of FMS among Malaysian and Singaporean rheumatologists. There appears to be different levels of belief, knowledge and perceptions of FMS among rheumatologists themselves. Some experts disagree as to whether they are real or an imagining construct of physicians and some believe that FMS is not a discrete condition<sup>(11)</sup>. In a recent survey among rheumatologists in Scotland, the majority believe that FMS is a distinct clinical but not pathological entity<sup>(12)</sup>, while another study in France showed that only a quarter (23%) of their rheumatologists considered FMS a disease<sup>(13)</sup>. No such study was ever performed in this region, thus this study will provide an opportunity for us to record our understanding, perceptions and awareness

of this condition.

## METHODS

A total of 48 three-page questionnaires (Appendix 1) were sent to all rheumatologists (specialists and trainees) in Malaysia and Singapore. The questionnaires included the professional background of the physicians, their practice settings, and a series of questions regarding their perception of FMS, diagnostic tests and its treatment. For those in the academic institutions, they were also asked about the inclusion of FMS in the undergraduate teaching curriculum.

## RESULTS

A total of 23 (82%) respondents from Malaysia and 20 (100%) from Singapore completed the three-page questionnaire that addresses different aspects of their awareness and perception of FMS (Fig. 1). The majority of rheumatologists in Malaysia (91%) and Singapore (95%) believe that FMS is a distinct clinical entity. However, only two (9%) Malaysian rheumatologists and one (5%) Singaporean did not think that FMS is a distinct entity. 16 (69%) Malaysian rheumatologists believe that FMS is an illness while only seven (31%) believe it is a disease; and 12 (60%) Singaporean rheumatologists believe FMS is an illness and eight (40%) of them regarded FMS as a disease (Table I). The majority of rheumatologists from both countries, 20 (87%) Malaysian and 18 (90%) Singaporean, believe that FMS is a mixture of both medical and psychological illnesses. However, only two rheumatologists from each country, 9% of Malaysian and 10% of Singaporean rheumatologists, believe that FMS is primarily a psychological illness. Only one (4%) Malaysian rheumatologist considered FMS as primarily a

**Table I. Results of the awareness and perceptions of FMS among respondents.**

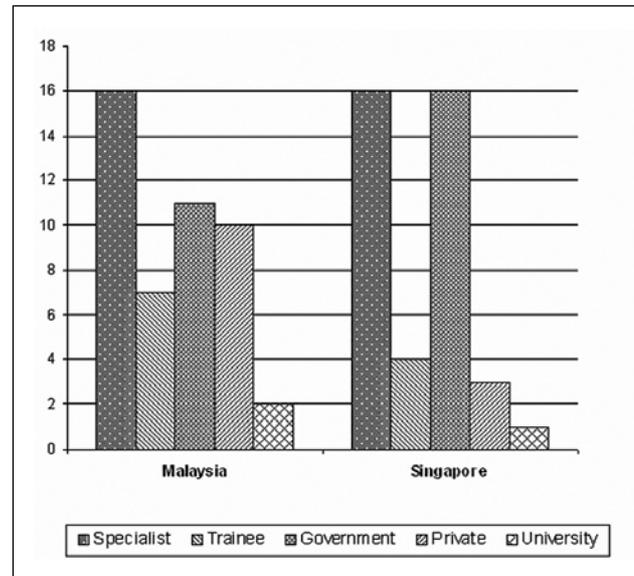
Questions		Malaysia n (%)	Singapore n (%)
A	Do you believe that FMS is a distinct clinical entity?	Yes	21 (91)
		No	2 (9)
B	Do you believe that FMS is an illness or disease?	Illness	16 (69)
		Disease	7 (31)
C	Do you believe that FMS is primarily medical, psychological or both?	Medical	1 (4)
		Psychological	2 (9)
		Both	20 (87)
D	Are you aware that there is an ACR criteria for diagnosis of FMS?	Yes	19 (83)
		No	4 (17)
E	If answer to above is "yes", did you use it to make a diagnosis?	Yes	14 (60)
		No	9 (40)

medical illness and none from Singapore believed so.

All the rheumatologists from Singapore are aware of the ACR classification criteria for the diagnosis of FMS; however, only 19 (83%) of their Malaysian counterparts were aware of it (Table I). Despite this, 14 (60%) Malaysian rheumatologists utilised the criteria to make the diagnosis and nine (40%) did not use it, while the majority of Singaporean rheumatologists (18 [90%]) did not use the criteria to make a diagnosis, and only two (10%) had used it (Table I). It should also be noted that, in daily clinical practice, those diagnosed with FMS may have had myofascial pain syndrome with multiple trigger points, benign joint hypermobility syndrome or chronic fatigue syndrome. 20 (87%) Malaysian rheumatologists ordered some form of blood tests, compared to 16 (80%) of their Singaporean counterparts ( $p=0.779$ ) (Table II). All rheumatologists from both countries prescribed medications for FMS (Table II). When asked to list their drug treatment of choice, these were, in order of preference: Tricyclic anti-depressants (82%), followed by simple analgesics (55%), selective serotonin re-uptake (SSRIs) (65%), and non-steroidal anti-inflammatory drugs (NSAIDs) (22%). Of seven respondents from Malaysia who have responsibility for organising rheumatology undergraduate teaching, four (57%) include FMS in their teaching. However, in Singapore, of 12 respondents, six (60%) included this topic in their teaching curriculum (Table III).

## DISCUSSION

FMS has been described as an emerging but controversial condition<sup>(14)</sup>. Our results demonstrate that the majority of rheumatologists from Malaysia and Singapore believe that FMS is a distinct clinical entity. Most of our rheumatologists believe that FMS is also an illness but not a “disease” by itself. Although it is increasingly accepted that FMS is a definable clinical entity<sup>(15)</sup> using the classification criteria<sup>(9)</sup>, the syndrome is still disputed. It is not surprising that physicians are unable to demonstrate FMS as a visible disease. It occurs in the context of



**Fig. 1** Distribution of the level of rheumatologists and their practice setting in Malaysia and Singapore.

unrevealing physical examination, and laboratory and radiological examinations<sup>(16)</sup>. Many physicians believe, from early years of their training, that a “true” disease is based on pathological changes in the tissues, whether macroscopically or microscopically; otherwise, if it fails to show these changes, it will be considered as a “non-disease” or regarded as a psychological entity. However, in the context of FMS, it is not an entity that can be described and explained; rather, it is a subjective experience comprising pain and fatigue<sup>(17)</sup>.

Hadler stated that FMS is a form of illness behaviour rather than a “disease”, escalated in vulnerable patients with particular symptoms, and argued that FMS is a specific entity<sup>(18)</sup>. Wolfe<sup>(19)</sup> also stated that there is little evidence that FMS is a disease and those who helped developed the FMS construct still consider it a syndrome; yet, according to him, FMS is still treated as a disease by the courts, by patient organisations, by the treating

**Table II. Respondents' views on investigations and treatment for FMS.**

Questions		Malaysia n (%)	Singapore n (%)
A	Do you order any blood tests to investigate FMS?	Yes	20 (87)
		No	3 (13)
B	Do you think that a blood test is necessary?	Yes	20 (87)
		No	3 (13)
C	Do you prescribe medication for FMS?	Yes	23 (100)
		No	0

**Table III. Inclusion of FMS in the undergraduate curricula.**

		Malaysia n (%)	Singapore n (%)
Do you include FMS in the undergraduate teaching curriculum?	Yes	4 (57)	6 (50)
	No	3 (43)	6 (50)

physicians, and often, by research scientists<sup>(19)</sup>. Lorentzen stated that FMS is not a disease entity, but the symptoms that are often reported supposedly reflect difficulties in coping with various types of mental stress<sup>(20)</sup>.

The majority of rheumatologists in this region (Malaysia/Singapore) believe that FMS is a mixture of medical and psychological illnesses. Very few respondents believe that it is primarily a psychological disease. The issue of psychological involvement has long been debated. In fact, some physicians believe FMS is no more than hysteria or malingering<sup>(21,22)</sup>. However, Merskey<sup>(23)</sup> and Capen<sup>(24)</sup> in 1989 and 1995, respectively, have good evidence that FMS is a psychological condition rather than a physical disease. Despite the fact that FMS patients tends to minimise or deny psychological symptoms<sup>(25)</sup>, the evidence is overwhelming that the burden of psychiatric disease is higher in comparison to controls. Many studies<sup>(26, 27)</sup> have shown that FMS patients have higher levels of psychological distress than rheumatoid arthritis patients, as well as more depression. However, one study found that FMS patients appear to be significantly less depressed when compared with depressed arthritis patients<sup>(28)</sup>.

In 1990, the ACR published criteria for the classification of FMS<sup>(9)</sup> at a large multicentre study, intended to identify classification (diagnostic) criteria for the syndrome with high sensitivity and specificity. Not surprisingly, most of Malaysian and Singaporean rheumatologists were aware of the ACR classification for diagnosis of FMS, but it seems that the Singaporean rheumatologists rarely use it as a tool to make the diagnosis. In the Malaysian scenario, the majority of rheumatologists use the ACR criteria to make a diagnosis. The difference is significant when comparing the two countries. These criteria facilitated epidemiological studies, clinical trials and observational research studies. It should not be solely used to make a diagnosis of FMS.

Katz et al demonstrated that the diagnosis of FMS, whether based on a clinical diagnosis, ACR criteria or survey criteria, are moderately concordant (72%–75%)<sup>(29)</sup>. Since there is no “gold standard” to diagnose FMS, all methods of diagnosis have utility. There are some limitations of these criteria<sup>(30)</sup>, especially in untrained

assessors, as the criteria are unlikely to be applied uniformly. In practice, the diagnosis is often made without formal tender point examination, patients may have the requisite tender points and yet not have FMS, and finally, tender points and widespread pain alone do not capture the essence of these syndrome. Currently, there is a work-in-progress study by the Working Group on Outcome Measures (OMERACT) for FMS in prioritising and standardising symptom domains and outcome measures in FMS<sup>(31)</sup>.

Rheumatologists from both countries generally arrange some form of blood tests to investigate or rule out other serious pathology such as connective tissue diseases (CTD), endocrinological diseases and occult malignancy, and the majority agreed that blood tests were necessary. FMS is a clinical syndrome that cannot be explained on current pathophysiological grounds, and there is a lack of specific laboratory or other diagnostic tests. Despite that, most rheumatologists still arrange for initial laboratory tests which include a complete blood count, comprehensive chemistry panel, erythrocyte sedimentation rate, thyroid function tests and muscle enzymes – all of which should be normal. Some physicians also request for antinuclear antibody (ANA) tests if fatigue is profound in FMS patients<sup>(32)</sup>. Fatigue is not a specific feature of FMS, but may be present in 40%–50% of patients with systemic lupus erythematosus (SLE)<sup>(33)</sup>. Fatigue is also a prominent symptom of primary Sjogren`s syndrome, and is in fact a subjective core outcome measure proposed in 2003 by the Working Group on Outcome Measures for Sjogren`s syndrome<sup>(34)</sup>. This syndrome is often a greater mimic of FMS compared to SLE because clinical symptoms (e.g. sicca symptoms) and signs can be less objective than those present in SLE. We feel that autoantibody testing should be included in the series of tests for FMS.

All the rheumatologists from Malaysia and Singapore prescribed some form of medication to patients with FMS. Although there is little evidence that most therapies usually employed in FMS have any substantial long-term benefit, drug therapies remain empirical. The tricyclic agents, which rheumatologists from both countries commonly prescribed, have proven efficacy in controlled trials<sup>(34)</sup>. SSRIs, other antidepressants, tranquilisers, muscle relaxants, anti-epileptics, NSAIDs, physical therapy, tender point injections, craniosacral release and stretching are among other treatments which are arguably useful in FMS.

Respondents who have a university affiliation were asked about FMS curriculum in their teaching. A variable response was given, as not many respondents from the university setting include FMS in their undergraduate curricula. Buskila et al reported that residents that have been given formal FMS teaching did significantly better in diagnosis of FMS<sup>(1)</sup>. Despite this, Blotman et al reported

that 93.7% of French general practitioners have not received any medical school training on FMS<sup>(13)</sup>. From our experience, most FMS patients initially turn to their general practitioners, and it usually takes a few years before they are finally referred to a rheumatologist. This delay, of course, poses an economic burden on the system caused by numerous tests and examinations. Primary care patients who had been diagnosed with FMS reported a higher rate of illness and healthcare resource use for at least ten years prior to their diagnosis<sup>(34)</sup>, suggesting that illness behavior may play a role.

Being diagnosed with FMS may help patients cope with some symptoms, but the diagnosis has limited impact on healthcare resource use in the longer term, possibly because there is little effective treatment. Suarez-Almazor et al demonstrated that primary care physicians frequently requested autoantibody tests in patients with fatigue and musculoskeletal complaints<sup>(36)</sup>. Most of these were negative as they were often requested in patients without CTD, resulting in low positive predictive values and questionable clinical utility. From our point of view, it is important to include FMS in our undergraduate teaching curriculum, as this disorder is more common than RA and SLE.

In conclusion, this study confirmed that there was a variation of perceptions and knowledge of FMS among rheumatologists from Malaysia and Singapore. The majority of rheumatologists recognised that FMS is a distinct clinical entity, and the illness was diagnosed by excluding other well-defined clinical diseases through a combination of clinical evaluation and screening tests.

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**APPENDIX I. Questionnaire sent to rheumatologists in Malaysia and Singapore.**

Tick the appropriate answer:

## General

Are you a	Specialist	
	Trainee	
Practice setting	Government	
	Private	
	University	

## Fibromyalgia perception

Do you believe that FMS is a distinct clinical entity?	Yes	
	No	
Do you believe that FMS is an illness or a disease?	Illness	
	Disease	
Do you believe that FMS is primarily medical, psychological, or both?	Medical	
	Psychological	
	Both	
Are you aware that there is an ACR criteria for diagnosis of FMS?	Yes	
	No	
If answer to the above is "yes", did you use it to make a diagnosis?	Yes	
	No	

## Investigations of FMS

Do you order any blood tests to investigate FMS?	Yes	
	No	
If answer to the above is "yes", kindly list down the tests you had ordered	1. 2. 3.	
Do you think blood tests are necessary?	Yes	
	No	
If "yes", kindly state reason(s)	1. 2. 3.	

## Treatment of FMS

Do you prescribe medication for FMS?	Yes	
	No	
If "yes", what medication would you prescribe? (kindly list them in order of preference)	1. 2. 3.	

Any other treatment modalities? If you are practising in an academic institution, kindly answer the questions below:

Do you include FMS in the undergraduate teaching curriculum?	Yes	
	No	
If answer is "yes", kindly state reason(s)	1. 2. 3.	

Thank you for completing the questionnaire.