

FIBROMYALGIA: PERSPECTIVE OF PATIENTS, MEDICAL STUDENTS AND PROFESSIONALSBeena Vasanthy¹, Vijayan Chandrathil Parameswaran Nair²¹Associate Professor, Department of Neurology, Government Medical College, Kottayam, Kerala.²Professor, Department of Medical Education, Government Medical College, Kottayam, Kerala.**ABSTRACT****BACKGROUND**

Fibromyalgia syndrome (FMS) had raised controversy including its existence. From early twentieth century, it was established as a disease, causing disability, where there are symptoms without signs, biomarkers or investigational abnormalities. It is common in all ethnic groups across countries. A considerable fraction of outpatients are FMS patients. So, this study was planned to assess the awareness of this clinical entity among medical professionals at different levels.

MATERIALS AND METHODS

Qualitative study using in depth interview was conducted among undergraduate (UG) medical students doing clinical posting, house surgeons and internal medical residents. Informal data collection was done from internists, orthopaedicians, psychiatrists & neurologists. All were interviewed at their work places. Enquiries were made regarding FMS, aetiopathogenesis, diagnosis, differential diagnosis, approach to FMS and management.

Patients were interviewed in neurology OPD. Data was collected in detail regarding symptomatology, number of specialty consultations, investigations, interference with work and relationships, economic burden incurred, drug treatment and loss of hope. Enquiry was done to know whether they were told about their disease. They were followed up.

RESULTS

Undergraduate students, house surgeons and residents were unable to diagnose FMS. Residents were able to diagnose, but occasional errors were observed. Attitude of some of senior consultants were sceptical. Most patients were unaware of the diagnosis.

CONCLUSION

Knowledge and attitude in relation with FMS is poor among medical students and clinicians. Patients like to get educated about their illness.

KEYWORDS

Fibromyalgia, Qualitative Study, Perspective, Medical Students, House Surgeons, Residents, Patients.

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BACKGROUND

Fibromyalgia syndrome (FMS) is a chronic illness with prevalence of up to 6.6% in general population. Prevalence is higher among women and connective tissue disorder patients.¹ Termed colloquially as rheumatism, Gowers in 1904 named this condition as fibrositis. Name was changed by Smythe to Fibromyalgia, acknowledging it as separate entity. Later, diagnostic criteria were proposed by American College of Rheumatology in 1990² and it is revised periodically amongst which latest was 2016 revision of 2010/2011 criteria.³ Patients present to different medical disciplines.⁴ Misdiagnosis is as high as 13% and most of them are managed without guidelines. Some may be over

investigated, over treated⁴ while others may be ignored. Residents and Consultants observe them as patients without signs but with symptoms. It is a diagnosis of exclusion⁵ even though there are criteria from American College of Rheumatology (ACR).⁶ Diagnostic difficulty is due to absence of clinical signs, no definite investigations and biomarkers.⁷ Due to multiple symptoms and lack of clarity in communicating them, patients often present late to various departments. Mean delay in diagnosis is 2.3 years.⁵ Earliest diagnosis is usually after minimum period of around one year. Patients present to minimum three specialists before getting diagnosed as FMS.⁴ 95-98% present to Primary Care Physicians (PCP) and 60% to Neurologists. Other specialists seen are internists, psychiatrists, rheumatologists and rarely orthopaedicians. One third specialists are of the opinion that FMS do not exist & around half of them are not aware of the 1990 criteria for FMS. There is risk of missing serious illness if red flags are ignored.⁴

FMS can cause diagnostic dilemma.^{5,6,7} Symptomatology are variable like wide spread pain, sleep problems, fatigue, cognitive dysfunction, amnesia, dysuria, numbness, depression, headache, giddiness, abdominal pain, motility

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disorders and many other symptoms which they are unable to explain and unable to localize. Diagnosis is difficult when other diseases like rheumatoid arthritis and osteoarthritis, endocrine diseases like hypothyroidism, diabetes, neurological diseases like carpal tunnel syndrome, migraine, sleep apnoea syndrome and psychiatric disorders like depression coexist with FMS.^{8,9}

Pathophysiology of FMS is not well established. Postulations are there that it could be due to either peripheral or central mechanisms. Central sensitization decreases in externally directed behaviour and small fiber neuropathy are some of them. Central sensitization causes non-painful stimuli felt as painful. It may also occur due to defective sensory processing.

FMS like symptoms can occur in various chronic illnesses and they are called Red flags.⁵ They are symptom onset after 70, unexplained weight loss, fever, pain interfering with sleep or sleep apnoea, weakness or wasting, gait abnormalities, reflex changes, arthritis, rashes, lymphadenitis, cardiac signs, pain confined to specific region which could be organic like penetrating backache or neurological symptoms or presence of cancer.

Clinicians will go for diagnostic measures only when other differential diagnosis are to be ruled out. But most often, patients undergo innumerable investigations especially in peripheral centers.¹⁰ It reflects lack of awareness of FMS. The treatment required is step wise approach with a holistic view including cognitive behavioural therapy with pain management.¹¹ Combined approach with patient education, meditation and movement therapy aiming at body-mind intervention works best. Another approach is to combine pharmacological treatment with other therapies. Patients and health care workers should work hand in hand. In major crowded hospitals FMS patients may get admitted as they are not screened well at peripheral level. The awareness about this entity was looked into at various levels of medical personnel and patients.

Objectives

1. To assess knowledge and attitude of medical students and professionals towards Fibromyalgia Syndrome.
2. To assess knowledge about their illness among patients of FMS.

MATERIALS AND METHODS

Study Design- Qualitative design.

Study Setting- Government Medical College Hospital, Kottayam which is an 1800 bedded teaching hospital with all broad and super-specialties.

Four undergraduate students of eight & ninth semesters each, four house officers, four internal medicine junior residents were interviewed. Interviews with consultants were informal discussions. Consultants chosen were Neurologists, Internists, Orthopaedic surgeons and Psychiatrists They were enquired regarding awareness of FMS, symptomatology, diagnostic criteria and points for suspicion about it. The students and doctors were randomly

selected without bias. Method of data collection was in depth interview.

Patients and their relatives were selected randomly who came to Neurology OPD. They were confirmed to have Fibromyalgia as per revised 2016 diagnostic criteria.³ Six hundred patients were interviewed.

Patients were interviewed in depth and asked regarding the duration of symptoms, communication difficulties, number of consultations and specialists chosen, investigations underwent, treatment offered and outcome. Family members were also interviewed. This study was for generating concepts. Hence numbers were not analysed.

Study Period

Institutional Review Board Clearance was obtained on 28/03/2017. Study was done for six months from that date.

RESULTS

None of the medical students were aware of FMS. Some House officers were having partial awareness of some pain condition affecting females, equated with tender points. They thought it to be functional or hysterical. They were not aware of the criteria or disabilities caused by FMS.

Junior residents of internal medicine were aware of FMS as pain syndrome. Knowledge regarding pathophysiology was grossly inadequate. Criteria, prevalence, association, economic burden and disability were not thought of. On querying regarding management, most would offer NSAIDs or if not responding Amitriptyline. Regarding non-pharmacological treatment, awareness was lacking.

Consultants were aware of entity, not bothered about diagnostic criteria and most of them were sceptical. They were not concerned about economic burden and disabilities. It was not an exam topic, benign and devoting time for this was not worthwhile.

Patients across all financial categories were affected equally. Females outnumbered males, ratio being 20:1. Even though reportedly disabled, none stopped working or changed work due to FMS.

Patients were concerned regarding attitude of family members, who were frustrated when patients complain of pain and other symptoms. Majority of family members thought symptomatology is fabricated, a means of escape from responsibilities, or peri and post-menopausal issue. This prevented them from seeking medical help and patients thought that they were silent life-long sufferers.

Patients had many symptoms in addition to wide spread pain. Headache, neck pain, back and low backache, fatigue, giddiness, visual & auditory symptoms, sleep issues, nonrestorative & inability to sleep, non-localizing numbness, and urinary symptoms. Periarthritis shoulder, carpal tunnel syndrome, hypothyroidism, connective tissue disorders, diabetes, and hypertension were comorbid diseases. Patients came after a mean delay of around 2 years, of which the longest was 10 years. For some, it was their first visit. They had visited PCPs, internists, orthopaedicians, psychiatrists & neurologists. Many had undergone number of investigations like neuroimaging of brain, cervical and

lumbar spine, and hormonal profiles with cortisol assays or haematological work up for cancer or connective tissue disorders.

Medical help was sought only when they had co-occurrence of other conditions like peri-arthritis shoulder or carpal tunnel syndrome, positioning vertigo etc. Many were anxious with fluctuations in affect. The FMS symptoms were not addressed effectively when they did consultations to various medical personnel including specialists. When they sought medical help, they frequently encountered multiple referrals. Patients with long duration symptoms had frequent flares in rainy season.

Most of them found it difficult to communicate symptoms, as experience could not be spoken out clearly enough to be understood, hence confusing doctors. This caused embarrassment, and a few became defaulters after an initial visit.

Consultation with specialists led to advanced diagnostic tests; like imaging of brain, cervical or lumbar spine, in addition to haematological, metabolic profiles. Others were investigated for hormonal profiles like thyroid function tests, cortisol assays and prolactin. Nerve conduction study, extensive work up for connective tissue disorders and cancer were also done.

They were variably treated with NSAIDs on symptomatic basis, mostly by general practitioners. Few could explain the disease, treatment and prognosis. Almost none suggested non-pharmacologic treatment. They were initiated on propranolol, flunarizine and a few on pregabalin, amitriptyline.

Most of the patients had fluctuations in severity of symptoms; but were able to continue functioning with suffering when it was milder, but took treatment as it became unbearable. All wanted to get rid of the burden.

Patients when informed regarding nature of condition and nonpharmacological methods of treatment, it was unacceptable; with requests for medications. On follow-up many could be coaxed to stop medications and continue with cognitive behavioural therapy with physical exercises including yogic postures and indigenous liniments. Many liked the "concept of benign illness of nerves and connective tissue with pain processing abnormality."

DISCUSSION

FMS existed for centuries,⁵ but nihilistic attitude¹² continued till recently. At present there are ACR diagnostic criteria³ and defined lines of management.⁵

Significant knowledge gap of undergraduate students¹³ and house-surgeons for FMS was reported which was revealed here. This should be viewed with information from US where preclinical students are unaware but clinical clerk men knew partially of FMS.¹⁴ Residents are of view it is a benign and low priority illness. By 1992, FMS was recognized as illness and before that it was considered to be possibly psychological or malingering, not having true disease.¹² Several studies showed diagnosis of fibromyalgia to be difficult. Medical students and house-surgeons did not have awareness or expertise in diagnosing and managing FMS.¹⁵

90% of primary care physicians (PCP) had difficulty in differentiating symptoms of FMS from other illnesses. This is significant when medical students and house surgeons who are going to become primary care physicians and this knowledge gap should be addressed.^{12,15,16}

Rheumatologists diagnosed it with 90% confidence seconded by neurologists (77%), seen in China also. Psychiatrists and primary care physicians had least confidence. The confidence in diagnosing suggests expertise in managing chronic painful conditions. There is need for improved physician training in the diagnosis of FMS, particularly PCP.

Attitude to FMS is challenging.¹³ House-surgeons and internal medicine residents also shared nihilistic attitude towards FMS. The attitudes of students, house surgeons and residents are affected due to¹³ 'hidden curriculum' observing attitudes and actions of senior colleagues & teachers. Even though FMS is a common disease, awareness is lacking among students and young physicians, indicating either distorted attitude or adherence to age old beliefs of its nonexistence. Both demand remedial measures.^{12,13}

One quarter of PCP and one tenth of specialists including rheumatologists continue to believe that FM patients are having psychological issues or are¹⁶ malingerers.¹⁷ Physicians and patients felt that doctors should spent more time which results in improving diagnostic issues. It will also help in developing healthy communication & therapeutic relationship, in diseases like FMS where pathophysiology, diagnostic testing and treatment are imprecise. FMS should be managed at PCP level, where he/she could acquire necessary skill and time to provide physical and emotional support. Patients have neurobehavioral dysfunction in form of inability to recognize self-psychological functioning, defective social cognition skills and emotional functioning.^{17,18} This was reflected in reduced self-esteem, delay in seeking medical help and communication issues. FMS patients are referred to as having "problems in their mind rather than true disease", which reduces their self-esteem. This is seen in study where many lacked self-esteem including addressing their current issue.

Diagnostic problems could be overcome by asking direct questions as per the criteria in ACR or use of validated questionnaire like Fibro Detect Screening tool¹⁹

FMS diagnosis is essentially clinical, investigations planned when there are red flags in presentation. Hence detailed laboratory workup, metabolic profile or neuroimaging are not indicated in FMS.²⁰ Focused history and tailored physical examination with base line investigation will be sufficient. Further Laboratory workup may only be indicated if coexisting conditions like connective tissue disorders or hypothyroidism is suspected.²¹

Better health outcomes and quality of life for patients with FMS can be ensured by developing effective treatments from better its understanding. Clinicians, both individually and in collaboration with other health care professionals and their patients, can improve patient care with vigilant recognition and diagnosis of FM.

Cognitive problems, paresthesia, carpal tunnel syndrome, headache, backache, giddiness, urinary symptoms etc. were investigated on symptom-based approach leading to significant financial and emotional strain. Treatment with NSAIDs, bed rest, and surgical procedures caused emotional strain and worsening of existing condition. FM patients had more specialist referrals, had diagnostic tests than patients with Diabetes or Hypertension. The overall expenditure was comparable among the three groups.²²

Thus, creating awareness & competence to diagnose FMS effectively and offering appropriate treatment should be made possible.

Perspective of Patients

Women were significantly affected more than men,²⁰ which is common in all studies. The reason for female predilection should be investigated. All work groups were affected, but low-income group were represented more. Reason could be setting in Govt. Hospital where health care is free.

Health seeking delay may be due to difficulty in⁵ communicating symptoms and diagnostic issues due lack of awareness of FMS Diagnosis can be difficult due to coexistence with other diseases. Innumerable investigations²¹ and unscientific treatment could be avoided, which adds to economic and psychological burden. This is seen presently.²⁰

Unlike in West, FMS did not significantly affect salaried work, as most continued to work. If quality of work was affected is not clear as interview was only with patients. Private life suffered with some spouses and children thought disease to be in their minds, which interfered with self-esteem.

During first visit when they were advised⁵ CBT without drugs, most were requesting medications. Subsequently when they were informed regarding nature of illness, many opted for CBT with plan to consult on flares. This shows importance of patient education.^{23,24}

CONCLUSION

Teaching and learning about FMS needs to be consistent to improve knowledge and attitudes of clinicians. Undergraduate students should be sensitized to FMS so that they understand & diagnose patients with FMS. FMS should be included in medical curriculum so that PCP can diagnosed and treated with confidence.

Patients should be educated regarding illness. Drugs need be prescribed only when pain is disabling, and coping strategies fail.

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