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Original article

EpiFibro – a nationwide databank for fibromyalgia syndrome – the initial analysis of 500 women

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ABSTRACT

Introduction: Fibromyalgia syndrome (FS) is a common painful condition of the musculoskeletal system that is typically accompanied by several symptoms in other systems. In Brazil, the prevalence of FS is estimated at 2.5%. Here, we present the initial data from EpiFibro, a nationwide databank of FS patients seen in public and private settings.
Objective: The aims of this study were to assess how the diagnosis of FS was made, identify a set of clinical domains considered relevant by both clinicians and patients in cases of FS, analyse the impact of disease on patient quality of life, and compare the findings among patients of public and private services.
Methods: Based on the results of questionnaires, we analysed data corresponding to the first 500 women in the database. Questionnaires pertaining to demographic and clinical data and the Fibromyalgia Impact Questionnaire (FIQ), which was translated and validated for Brazilian patients, were completed by the clinicians and/or patients.
Results: Preliminary analysis of the EpiFibro databank revealed that female FS patients in Brazil reported a high impact of disease, as measured by the FIQ, a high prevalence of associated symptoms, and a low degree of education (consistent with the public health care

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in Brazil used mainly by the underserved). In addition, most patients perceived their pain as diffuse from the onset of disease.

Conclusion: Depression and anxiety were seen as the main triggers of FM symptoms, but a significant proportion of the subjects perceived work strain as the initial trigger. We also observed a delay of a few years in seeking medical help and examination by a rheumatologist.

EpiFibro – um banco de dados nacional sobre a síndrome da fibromialgia – análise inicial de 500 mulheres

RESUMO

Palavras-chave:
Fibromialgia
Qualidade de vida
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Introdução: A fibromialgia (FM) é uma condição dolorosa do sistema musculoesquelético, geralmente acompanhada de vários sintomas em outros sistemas, com uma prevalência no Brasil estimada em 2,5%. Apresentamos os dados iniciais do EpiFibro, um banco de dados nacional de pacientes com FM atendidos em serviços públicos e privados.

Objetivo: Avaliar como é feito o diagnóstico da doença, identificar um conjunto de domínios clínicos considerados relevantes por médicos e por pacientes com FM, analisar o impacto da doença na qualidade de vida dos pacientes e comparar os achados entre pacientes de serviços público e privado.

Métodos: Foram analisadas as respostas das primeiras 500 mulheres nesse banco de dados. Esse banco de dados foi baseado em um questionário contendo dados demográficos e clínicos. O Fibromyalgia Impact Questionnaire (FIQ), traduzido e validado para o Brasil, foi preenchido pelos médicos e/ou pacientes.

Resultados: Uma análise preliminar do banco de dados EpiFibro revelou que as pacientes com FM no Brasil têm um alto impacto da doença avaliada pelo FIQ, uma alta prevalência de sintomas associados, um baixo grau de educação (um achado que pode ser explicado pelo fato de a saúde pública no Brasil ser usada principalmente por aqueles desfavorecidos socialmente) e a maioria percebe a sua dor como sendo difusa a partir do início da doença.

Conclusão: Depressão e ansiedade são percebidas como as principais causas dos sintomas da FM, mas uma quantidade significativa considera o esforço no trabalho como o primeiro gatilho. Há um atraso de poucos anos em busca de ajuda médica e para chegar ao reumatologista.

Introduction

Fibromyalgia syndrome (FS) is a painful condition that is highly prevalent in the global population. In Brazil, the prevalence of FS is estimated at 2.5%.[1] FS is characterised by chronic musculoskeletal pain and is usually accompanied by various other symptoms unrelated to the locomotor system. The manifestations of this disease depend on social, psychological, and cultural factors, among others, which makes the clinical expression of this disease highly varied and requires the use of different therapeutic approaches. Moreover, there is critical need for epidemiological studies on FS in Brazil.

The EpiFibro (*Estudo Epidemiológico da Fibromialgia no Brasil* [Epidemiological Study of Fibromyalgia in Brazil]) was created to analyse the epidemiology of FS and its comorbidities across Brazil. Using suitable on-line questionnaire, this database sought to provide better information for the assessment of diagnosis, treatment and impact of this disorder in the Brazilian society.

The objective of the current project was to assess how the diagnosis of FS is carried out, including the time required to perform a diagnosis; identify a set of potential clinical domains in FS cases, which were considered relevant by doctors and patients; and analyse the impact of the disease on the quality of life of patients. We also sought to identify the most commonly used treatments and assess whether there were differences among private and public health care systems. With this information, we hope to shorten the time required for diagnosis, improve FS diagnosis, treat patients earlier, provide more adequate treatment, and improve the quality of life of patients.

Materials and methods

The questionnaire was divided into 3 parts: 1) the registration form for the physician, which was completed only once using registration data obtained by the assistant physician, pertaining to how the diagnosis of FS was performed as well as the physician's opinion regarding the occupational aspect of FS; 2) the registration form for the patient, containing an initial page presenting data on diagnosis and treatment that was completed by the physician, with the remainder to be self-completed pertaining to registration and epidemiological data and the details of the patient's symptoms; and 3) the patient follow-up sheet, which was completed during the first 3 consultations following the initial assessment; this form was available online and was completed jointly by the physician and the patient.

All patients completed an informed consent form, and the project was approved by the Research Ethics Committee (Comitê de Ética em Pesquisa – CEP) of the Hospital das Clínicas of the Universidade Federal do Paraná.

A standardised questionnaire was also used in the investigation, which was completed via the internet by physicians who provided care to FS patients, both in the public and private sectors. All information was entered online in the respective databases for tabulation. Subsequently, these data were scanned on the website (www.renaprom.com.br) and then encrypted for access only with permission of the Brazilian Society of Rheumatology (Sociedade Brasileira de Reumatologia – SBR), which was responsible for the reliability of the project.

Based on the results of these questionnaires, data from the first 500 women were analysed. All patients were assessed by rheumatologists, and all met the FS criteria of the American College for Rheumatology (ACR) 1990.[2] A questionnaire containing demographic and clinical data and the Fibromyalgia Impact Questionnaire (FIQ), which was translated and validated for Brazilian patients, were completed by the respective physicians.

The results of quantitative variables were expressed as the mean, median, minimum value, maximum value, and standard deviation. The results of qualitative variables were expressed as frequencies and percentages. For comparison of groups defined by the health care setting (public or private) with quantitative variables, Student's t-test for independent samples or the nonparametric Mann-Whitney test were used as appropriate. Comparisons of the qualitative variables were performed using the Chi-square or Fisher's exact test. P values < 0.05 were considered statistically significant. Data were analysed using the *Statistica v.8.0* computer software.

Results

Patients treated in the public setting comprised 70% of the sample. The mean age was 50.16 years (± 10.85), with a minimum age of 17 years and maximum of 89 years (median of 51 years). The majority (59.4%) of patients were married (Fig. 1), and approximately one-third had not completed elementary education (Fig. 2). Regarding the occupational activity of the patients, 31% were employed, 21% were housewives, and 34% were unemployed or retired (Fig. 3). The household income for the vast majority of the families of the patients (73.4%) was less than R$ 2,000.00 per month (Fig. 4).

Regarding the patients' perception of what triggered their FS symptoms, 39.4% considered certain working conditions and 51% consider anxiety or depression to be the trigger. Some of the patients believed their symptoms had resulted from more than a single cause (Fig. 5).

Most of the patients stated that their pain had started as diffuse (70.2%). Approximately 25% of the patients waited more than 3 years to consult a doctor, and 42% waited more

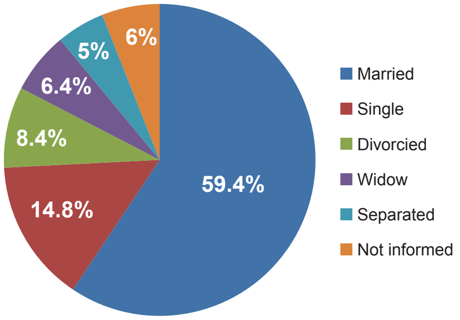

Fig. 1 – Marital status

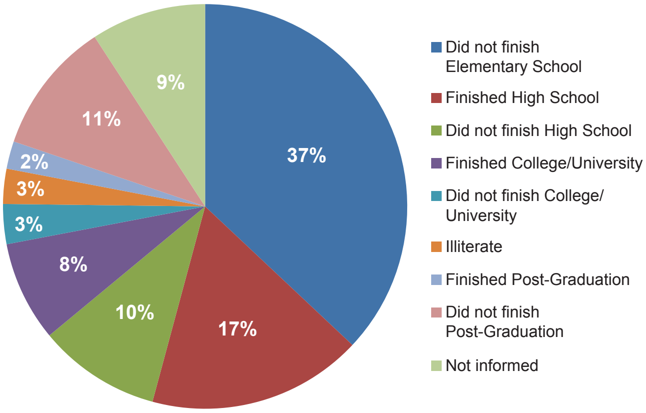

Fig. 2 – Educational level.

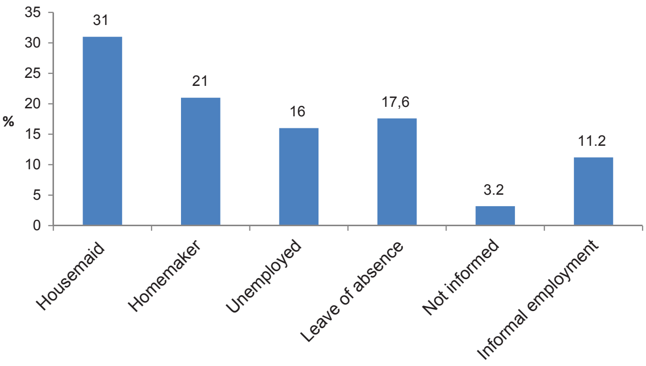

Fig. 3 – Occupational activity.

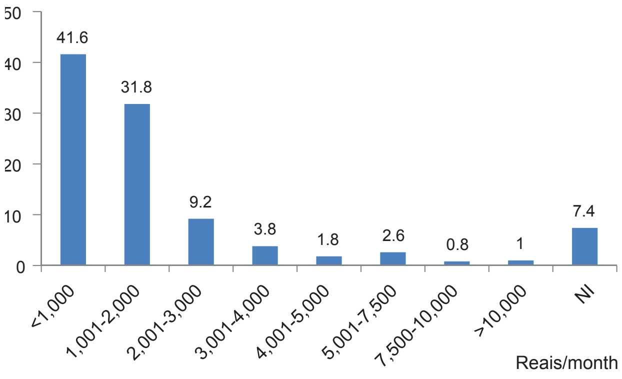

Fig. 4 – Percentage of family income.

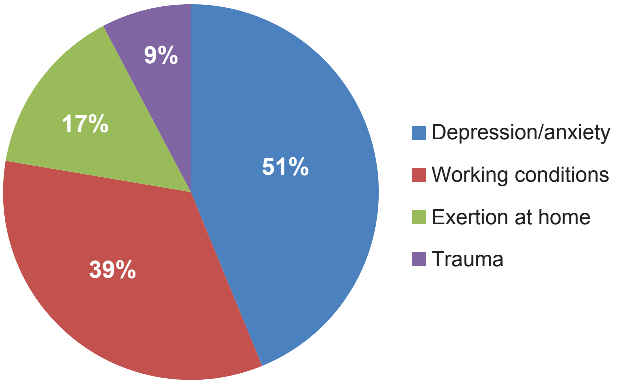

Fig. 5 – Patients' opinion regarding triggering factor.

than 3 years to consult a rheumatologist. Most patients first consulted with a general practitioner or an orthopaedist to evaluate their complaints.

Approximately 55% of patients were diagnosed at the time they entered the databank, and approximately 43% were follow-up patients; we did not obtain this type of information for approximately 2% of patients. Among the 277 patients who were diagnosed when they entered the databank, approximately three-quarters (74.37%) reported pain for more than 3 years, 70% had visited more than 3 physicians before the diagnosis was made, and 44% of patients had only consulted a rheumatologist after a period of 3 years from the first consultation with another medical professional.

The main symptoms associated with FS included sleep disorders (86%), fatigue (84.6%), anxiety (77.2%), paresthesia (75%), and headache (72.6). The average number of symptoms associated with chronic musculoskeletal pain in these patients was 8.6 ± 3.2 (0-15). These patients had an average of 13.74 tender points. The average FIQ score was 60.82 (with a maximum value possible of 100), which was considered to indicate a significant impact of FS on the patients' quality of life.

Table 1 shows that the patients from the public sector reported lower levels of education compared to private-sector patients, who also reported more diffuse pain in the beginning of the disease (77.71% vs. 55.49% in private patients). However, there was no difference between these groups regarding the FIQ scores (60.65 vs. 62.67, respectively).

Discussion

Public health care patients represented the majority of this sample. In addition, a substantial proportion of the patients analysed did not complete elementary education, indicating that they possessed a low educational level, which put them at a disadvantage in the labour market and in other life situations. More than half of the patients were not employed and were considered housewives, retired or unemployed. Moreover, approximately three-quarters of the patients reported a low family income, and psychosocial factors such as these have been shown to interfere with FS symptoms.[3]

Table 1 – Public and private patients.

	Public	Private	P
Finished elementary school	32.6%	4.4%	0.001
Initially diffuse pain	78%	55%	0.001
Mean FIQ	60.65%	62.67%	ns

Many patients cited working conditions and/or psychological disorders, particularly depression and anxiety, as factors responsible for the onset of their disease symptoms. However, there is no scientific evidence to suggest that FS has an occupational origin or that this chronic pain syndrome is caused by depression, anxiety, or other psychogenic illness. Although a few articles published in the 1990´s related trauma in the workplace to the onset of FS,[4-6] there is insufficient data in the literature to characterise such causality. Moreover, previous studies have been conducted with small patient samples or were documented as isolated case reports.[7,8]

It remains unclear whether FS symptoms worsen when patients are subjected to strict criteria of productivity and pressure in the workplace. However, the biomechanical limits of these patients have yet to be established, and well as the impact of any reduction, modification, or elimination of specific tasks they perform. Systematic reviews suggest that there is currently no work-related intervention strategy that can be considered effective for the occupational aspects of disease in these patients.[9,10]

Importantly, as with any other chronic pain syndrome, motivation at work can be influenced by social and psychological factors. For example, it is known that patients with chronic pain tend to experience worse symptoms when they are also affected by associated psychological disorders. A study in Brazil found that 30% of FS patients exhibited severe depression and 34% moderate depression, and this study further showed that 70% of patients demonstrated significant anxiety and 88% showed a high state of anxiety.[11] Data from the present study are in full agreement with the findings of other studies, which have shown that FS patients have a significantly higher prevalence of depressive disorders and anxiety when compared to controls. In addition to their high prevalence, psychiatric disorders and FS also exhibit sociodemographic and clinical similarities.[12] In particular, a heterogeneous series of disorders, mainly involving the autonomic, neuroendocrine, and neuropsychiatric systems, can be observed in these patients, and the chronic state of psychophysical pain in FS adversely affects the quality of life, performance and mood state of patients. Therefore, many factors indicate a common pathophysiology between FS and various types of psychiatric illnesses, including changes in neurotransmitter systems, which may represent a common underlying mechanism.[13,14] Furthermore, many FS cases may benefit from the help of an expert in the field of mental disorders. However, it should be noted that there is no scientific literature to definitively show that FS is caused by a psychiatric disorder.[15]

Most patients in the present study reported that their condition began with diffuse pain, yet a substantial portion of patients took more than 3 three years to seek medical help and consult a rheumatologist. These findings indicate considerable delayed diagnosis and hence delayed onset of treatment. It was also observed that a significant number of patients consulted more than three doctors before receiving a diagnosis, which likely resulted in wasted time, unnecessary direct and indirect costs, and increased levels of stress. These data show that patients need better guidance and better access to specialists.

This study also found that the main symptoms associated with FS included sleep disorders, fatigue, anxiety, paresthesia, and headaches in over 70% of patients. The average number of associated symptoms (approximately nine) was another important finding, and this high prevalence of associated symptoms is similar to that reported in another study conducted in Brazil, which observed, in decreasing order of prevalence, stiffness, sleep disorder, fatigue paresthesia, impaired memory, headache, palpitation, dizziness, bloating, and chest pain in at least 70% of FS patients examined.[16] These findings reflect the major symptoms of this syndrome and the care that must be taken in diagnostic assessment, particularly the use of good propaedeutics and proper knowledge of the wide range of differential diagnosis.[17,18]

In addition to the large number of reported symptoms, the elevated tender point and FIQ values that were obtained in this study reflect the significant impact of this disease on the quality of life of patients. These data further indicate that the therapeutic approach should be quickly established and that treatment should be comprehensive and involve multiple strategies (both with and without medication).[19,20]

Although public health care patients demonstrated lower levels of education and reported more diffuse pain since the onset of symptoms compared to private care patients, they did not differ in FIQ values. This finding suggested that the impact of the disease was equally significant in both patient groups, a result that differs from that observed previously in the international literature.

Conclusions

This pioneering program entitled EpiFibro was created with the goal of improving the quality of care for patients with FS.

FS is a chronic pain disorder characterised by multiple symptoms, particularly diffuse pain in the musculoskeletal system. This syndrome has a negative impact on many domains of the patients' lives, including performance, motivation, and quality of life. FS also has financial consequences for patients and the health care system due to repeated spending on diagnostic assessment and treatment.

This preliminary analysis of the EpiFibro databank revealed that many women with FS in Brazil have a low educational level, are poorly informed about their disease, and are slow to seek medical help and the advice of a rheumatologist. In fact, we found that diagnosis could take several years to be performed. Our findings also revealed that these patients have a high prevalence of associated symptoms, experience a significant negative impact on their quality of life, and suffer from a significant delay in initiating treatment.

Conflicts of interest

The authors declare no conflicts of interest.

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