

PERCEPTION AND IMPACT OF PAIN ON PATIENTS WITH FIBROMYALGIA

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Resumo

Enquadramento A Fibromialgia (FM) é uma doença incapacitante. Um dos referenciais que sustentam o conceito de FM é o de ausência de processo inflamatório associado à dor. O outro é o da existência de pontos musculares sensíveis. É, por isso, fundamental uma profunda compreensão do que é esta dolorosa e debilitante condição.

Objetivos- Caracterizar a dor em doentes com fibromialgia; Perceber a influência/Impacto da dor na vida dos doentes com fibromialgia

Material e Métodos - É um estudo descritivo-correlacional. A amostra é constituída por 221 indivíduos, 4 do género masculino e 217 do género feminino. Hipótese – A perceção da intensidade, manifestação, evolução da intensidade da dor e índice de dor generalizada influenciam os doentes de FM. Os instrumentos foram a Escala Numérica da Dor (EVA), a Manifestação da Dor e o Índice de Dor Generalizada.

Resultados - A amostra é maioritariamente do género feminino (98,2%), com uma idade média de 45 anos, que reside num meio urbano (79,6%), é casada ou vive em união de facto (71,9%), vive com familiares ou outros (89,1%), tendo concluído o ensino secundário (49,3%) e estando actualmente empregados (42,1%). A intensidade da dor apresentada pelos fibromiálgicos tem um valor médio de 7,59. O Índice de Dor Generalizada apresenta um valor médio de 11,84. A perceção da intensidade da dor e a manifestação da dor condiciona o doente com FM.

Conclusão - A intensidade da dor percebida pelos fibromiálgicos do presente estudo é, na média das avaliações na EVA, igual a 7,59. A maioria dos indivíduos com FM classifica a sua dor como moderada ou grave. O Índice de Dor Generalizada tem um valor médio de 11,84, a maioria destes indivíduos sente dor em, aproximadamente, 12 de 19 regiões corporais e a sua dor manifesta-se continuamente.

Palavras-chave: Perceção, Dor, Fibromialgia.

ABSTRACT

Background: Fibromyalgia is a disabling disease. One of the characteristics of FM is the absence of swelling associated with the pain. The other is the existence of tender points. A deep understanding of what is this painful and debilitating condition is therefore essential.

Objective – to characterize the pain in patients with fibromyalgia ; To realize the impact this pain has on the lives of patients who suffer from fibromyalgia

Material and Method - It is a descriptive correlational study. The sample consists of 221 individuals, 4 males and 217 female. Hypothesis - The perception of pain intensity, the way pain manifests itself, the evolution of pain intensity and widespread pain index influence FM patients. The instruments used were the Visual Analogue Scale for pain (VAS), the Manifestation of Pain and the Generalized Pain Index questionnaire.

Results - The sample is mostly formed by females (98.2%), with an average age of about 45, who live in urban areas (79.6%), who are married or living with a partner (71.9%), are living with relatives or others (89.1%), have completed secondary education (49.3%) and are currently employed (42.1%). Pain intensity displayed by fibromyalgia patients has an average value of 7.59, the Generalized Pain Index shows an average value of 11.84. The intensity of pain perception and the manifestation of pain condition the way a patient with FM will be able to live.

Conclusion - The intensity of perceived pain by this study patients is, on VAS's average ratings, equal to 7.59. Most subjects with FM reported moderate or severe pain. The Generalized Pain Index has an average value of 11.84, the majority of these individuals feel pain in approximately 12 to 19 corporal regions and their pain is long-lasting.

Keywords: Perception, Impact, Pain, Fibromyalgia,

Introduction

Fibromyalgia (FM) is a commonly frequent and disabling rheumatic condition. In recent years chronic pain and discomfort have been common complaints that have forced more and more patients to seek help from Primary Healthcare (PHC) centres. Their complaints are expressed in many different ways, however misdiagnosis is often a reality and the patient may be seen as a victim of somatization or suffering from depression¹. Doctors, in turn, have frequently to deal with patients who are in pain or who show other somatic symptoms they can't adequately explain based on organic evidence².

This situation will cause an opposition between the approach chosen to find a cure through a symptomatic relief and the fact that we are assigning the cause of the patients' condition to psychosomatic disorders.

A deep understanding of what is this painful and debilitating condition, FM³, is therefore essential.

Unfortunately in the last decade the research focus on the incapacity caused by pain went from a biomedical vision to a holistic perspective, in which biomedical factors are important, but in which psychological and social factors have a great influence, too⁴.

Chronic pain is the most important FM symptom, both to patients and doctors⁵. "Pain is an unpleasant multidimensional experience which involves not only the sensory, but also emotional aspects of the person who experiences it⁶." An individual who suffers from FM and consequently has to live with this chronic pain will experience this feeling of pain but will also be forced to live a life which had to go through considerable changes. These changes in everyday life are caused by limitation of function, energy loss, mood changes and sleep disorders. Therefore it seems essential that we understand how these patients perceive pain so that we can provide them a proper intervention. All those factors justify an investigative study that focuses on pain assessment and on its impact on patients who suffers from FM, as well as on the analysis on the influence that socio-demographic and health variables has on these patients.

Material and Method

It's a descriptive correlational study. We asked the following investigation question: How can the pain felt by FM patients be characterized? The population we aim to study is formed by people suffering from Fibromyalgia. This sample is defined by the following selection criteria: medical diagnosis of Fibromyalgia and Fibromyalgia symptomatology showed for at least 3 months. The sample is composed of 221 Fibromyalgia patients, 4 male and 217 female individuals. Hypothesis 1- we anticipate the existence of a statistically significant relationship between the socio-demographic variables (gender, age, area of residence, marital status, family context, level of education, current professional situation) and the way pain is perceived by a Fibromyalgia patient; 2- the perception of the intensity of pain, the manifestation of pain, the evolution of the intensity of pain and the Generalized Pain Index influence FM patients. The instruments used were a socio-demographic questionnaire, the Visual Analogue Scale for Pain (VAS), the Manifestation of Pain and Generalized Pain Index questionnaires.

Results

The sample is composed of 221 individuals, 4 male and 217 female participants, aged between 19 and 68 which gives us an average age of 45,01. As far as the participants' area of residence is concerned, the results show that the majority of the interviewed people live in an urban environment (79,6%) and only 20,4% live in a rural area. When asked about their marital status, 71,9% of the participants answered that they are married or unmarried partners, 14,5% are divorced or widows/widowers and 13,6% are single. As for their family context, the majority of the participants told they are living with relatives or other people (89,1%), 10,9% only answered that they are living alone. The majority of the Fibromyalgia patients who participated in our survey (49,3%), graduated from high-school, 33,5% of them graduated from college and 17,2% had only finished the elementary school. 42,1% of the participants in this sample are currently employed, 24,9% are unemployed, 17,2% are on sick leave, 14,0% are retired and 1,8% had never had a job.

As far as the pain result was concerned, we could witness that 49,8% of the individuals reported a tolerable pain, 49,3% reported a moderate pain and 0,9% considered their pain to be light. Regarding the way pain manifests itself, the majority

(52,5%), refers that it is constant, then right after came those who said they feel pain several times a day (29,9%) and those who feel pain several times a week (12,7%). 5,0% state that they only feel pain several times a month. As for the intensity of pain felt during last month, 50,7% of the participants said that the pain had increased and 8,6% said it had decreased. The Generalized Pain Index shows a positive association with the impact of FM ($r=0.260$; $p=0.000$) : as the impact of FM increases , so does the Generalized Pain Index. The value of t has showed that this relationship is statistically significant ($t=3,983$; $p=0,000$).

Concerning the intensity of pain, the participants who reported feeling “light” pain were those who got a lower score regarding the impact of FM. The relationship between this variable and the impact of FM is statistically significant ($H=42,260$; $p=0,000$).

As far as the frequency in which the pain manifests itself, we witnessed that the individuals that feel constant pain are those who suffer a higher impact from FM and those who refer that they feel pain several times a month are those who suffer a lesser impact from FM. The differences are statistically significant ($H=12,372$; $p=0,006$).

We also saw a statistically significant difference between the impact of FM and the evolution of the intensity of pain: those who referred that the pain has been decreasing were those who got a lower score and the participants who answered that the pain has been increasing were those whose score was higher ($H=21,689$; $p=0,000$).

Regarding the hypothesis, we could see a statistically significant relationship between the Generalized Pain Index and the Fibromyalgia patients' life ($t=-3,259$; $p=0,001$). This relationship is inversely proportional ($r=-0,215$; $p=0,001$), in other words, as the Generalized Pain perception Index decreases, the quality of life of the FM patients increases.

Discussion

The sample of this study was composed of 221 people suffering from Fibromyalgia. 217 were female patients (98,2% of the participants) making this group much more representative than the one composed of male participants. The participants' age is between 19 and 68 which give us a 45,01 average age. Those values are quite similar to those from another investigation⁷ which recorded a 47,9 average age. That sample was mainly composed of female patients (77%). Similar results were found in a more recent study⁸ in which only 7,5% were male participants while 92,5% were female

patients. The patients' age was between 23 and 70 (49,93 average age). In another study⁹, which involved the application of a survey in five European countries (France, Germany, Italy, Portugal and Spain) to estimate the prevalence of FM in the general population, the average age of the 1125 participants was 56, higher than our study average age. As far as gender was concerned, thanks to that study, we discovered that, within the general population, Fibromyalgia is about twice as prevalent in women as it is in men⁹. An important percentage of the people who composed our sample lives in an urban area (79,6%). These results are in agreement with another investigation work composed of 93 participants, who were living in Portugal and in the Portuguese islands. This study found that 55,9% of the patients were living in the city. On the other hand, another study developed in Spain concluded that this condition is twice as prevalent in people who live in a rural area as it is in people who live in an urban environment¹¹. In the analysis¹⁰ we can see that 53,8% of the Fibromyalgia patients interviewed are married and that 17,2% are unmarried partners. The majority of the people who participated in our study (71,9%), are married or unmarried partners, too. 89,1% of them are living with someone. The majority of the FM patients who are part of our sample had graduated from high-school (49,3%) and 42,1% are currently employed. There are still significant percentages of unemployed patients (24,9%) and of people on sick leave (17,2%). 51,35 % of the 74 FM patients who were part of another investigative study¹² were employed, 20,27% were unemployed and 8,1% were on sick leave. These rates are quite close to our sample's. In the study previously mentioned¹⁰ we acknowledge that, contrary to the results we found in our study, the majority of the participants had only finished elementary school (46,2%). However the percentage of people who had graduated from high-school (39,8%) is not very different from the results we got in our study. As far as professional situation is concerned, the majority of the sample is employed as well (67,7%).

The exploratory analysis of another investigation¹¹ revealed that as number of years spent at school increases, the prevalence of the disease decreases. They realized that the disease had affected 4,8% of the participants who had very low academic qualifications and only 0,6% of patients who had graduated from college. That study also revealed that people who suffer from FM have lower employment rates (32,7%) than general population (52,3%).

The intensity of pain perceived by the patients who were part of our study is , according to VAS average ratings, equal to 7,59. In literature, similar results were

presented by other authors¹³ whose studies' objectives were to discover the relationship between the number of painful points and the intensity of the body perception of the central aspects of the condition (pain, fatigue, anxiety, depression) and their impact on the patients' function capacity.

The perception of the intensity of pain showed values that went from moderate to high, values which correspond to a 7,14 rate on the VAS evaluation scale. Lower rates were found in other investigations¹⁴ which sample was composed of 60 women suffering from FM. In that study, the perception of the average level of pain corresponded to a 5,92 rate. There are other studies that show higher rates, studies in which 8,65¹⁵ was the average rate of the intensity of pain referred by the patients.

Regarding this particular aspect, we think that we should stress out that the majority of the FM patients feel moderate or serious pain. When they were asked to answer questions about the intensity of their pain on a VAS questionnaire, 70% of the patients who were participating in investigative studies¹⁶ said that it was a severe type of pain (a 7 to 10 score) and 28% said the pain they were feeling was moderate (a 4 to 6 score). Our study also revealed that the majority of the patients (49,8%) say that their pain is severe/unbearable (a 8 to 10 score) and 49,3% said the pain they feel is moderate (a 4 to 7 score). Apart from this feeling of generalized pain which is usually severe or unbearable, the participants in this study refer that this pain is constant/long-lasting (52,5%) or, at least, many times during a day (29,9%). While conducting an investigation on the impact this condition has on the life of 800 Fibromyalgia patients, we could witness that 17% of those patients report they experience pain everyday of their lives, while 10% say they experience pain 4 to 5 days a week, 38% 2 to 3 days a week, 26% experience pain once a week and, at last, only 8% say they feel pain less than once a week¹⁶.

In the investigation we conducted, based on the new FM diagnosis criteria, we studied The Generalized Pain Index which revealed a 11,84 average rate for the patients who participated in our research. This means that the FM patients we interviewed for our study experience pain in 12 regions of their body on average. The work we did with 80 FM patients divided into two groups according to the place where they received medical treatment (outpatient rheumatology treatment or private practice) and which objective was to determine if there were significant differences in the clinical variables, revealed there are, on average, 14,7 tender points on the body of patients who were

receiving outpatient treatment and a 14,5 average number of tender points sites in patients that attended private practice¹⁷.

In another research⁸ we discovered a 13,43 average number of tender points sites in 97 FM patients. In literature we found a study about the correlation between the Fibromyalgia Impact Questionnaire (FIQ) and three different methods to assess the number of tender points sites the patients were referring to. The finger pressure method presented an average 14,86 score; the assessment done with a dolorimeter show a 11,81 score and the myalgic responder index showed a 24,61 score¹⁸. All the results presented in those studies about the number of tender points are quite impressive. However, as we pointed out during this study theoretical phase, the tender points counting is a dubious and unreliable method to fully express how serious this condition is¹⁸.

Since there are no research done based on the Generalized Pain Index yet, and because this index shows a strong correlation with tender points counting, we used these studies for comparison.

When we analyzed the relationship between pain, the main FM characteristic, and the impact of the syndrome, we were able to see the association that exists between the latter and the intensity of pain, with how often the pain is experienced, with the evolution of the intensity of pain and with the Generalized Pain Index.

As far as pain intensity is concerned, the patients who referred they usually experience light pain were those who got a lower score regarding FM impact, while those who experience severe/unbearable pain got a higher score. The relationship between those two variables is thus highly significant. Other results are consistent with this conclusion: they have also found a highly significant relationship between the intensity of pain and the FM impact¹⁵. These results were evident in other studies¹⁶.

Conclusion

Chronic pain is an experience influenced not only by physical factors, but also by emotional and cognitive factors. The Behavioural Theory of Pain¹⁹ enhanced the importance of the emotional, cognitive, behavioural and cultural aspects in FM patients' assessment and expression of pain. Personal beliefs, like self-efficacy for instance, are essential to help people face chronic pain. This belief has relevant consequences on the way patients deal with health problems like chronic pain and it can affect how the patient responds to the disease and to the treatment. It is seen as

playing a mediating role in the therapeutic changes. Beliefs can influence the way people live their pain. However, since they are culturally acquired, they can be changed. Therefore the success of the treatment depends often on changes that will affect the cognitive and motivational components of pain. The concept of self-efficacy may be very useful to modify behaviours that are less adaptive when dealing with pain.

Being able to assess this aspect in patients that experience chronic pain may help direct the care provided and improve the outcome of the treatment¹⁹. According to data contained in the “Pain Proposal”, at European level, chronic pain affects one in every five Europeans, that is to say 19% of the population. Chronic pain affects about 36% of the adult population in Portugal, which corresponds to nearly three million people. This condition has severe consequences in these people’s well-being, in their capacity to work and perform their daily tasks. Nearly 50% of the patients who experience chronic pain confess that this pain has a moderate or serious effect on their economical and professional activities, 4% have lost their jobs, 13% chose early retirement and 17% were diagnosed with depression²⁰.

Chronic pain treatment is delivered mainly in Primary Health Care (PHC) centres because of its high prevalence. Pain is the most common- 50 to 70% of consultation reason²¹- complaint in any healthcare centres consultation. PHC centres are the first line of treatment in health care and obviously it’s there that the first assessment and intervention in pain control are performed. Keeping this in mind, setting up a Chronic Pain Nursing Centre makes perfect sense. It is easier in PHC centres, through a regular and programmed medical follow-up performed by nurses, to achieve a better pain management and the rehabilitation of the patient’s physical, social and professional function, using a holistic approach and a model which is based on the patient’s understanding, on humanity and on the respect of the person’s individuality. Seeking healthcare centres to be relieved from suffering is a normal situation for a patient who experiences chronic pain. It seems that nurses, whose activity and proximity to patients will make it easy to establish bonds with them, will be the most suitable healthcare professionals to provide these patients with the emotional and psychological support that they need. Besides, PHC centres make it possible for families to get involved in the rehabilitation process.

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