Assessing knowledge on fibromyalgia among internet users

Felipe Azevedo Moretti[1], Roberto Ezequiel Heymann[2], Valdecir Marvulle[3], Daniel Feldman Pollak[4], Rachel Riera[5]

ABSTRACT

Objective: To assess knowledge on fibromyalgia in a sample of patients, their families, and professionals interested on the theme from some Brazilian states. **Methods:** Analysis of the results of an electronic fibromyalgia knowledge questionnaire completed by 362 adults who had access to the the support group for fibromyalgia site (www.unifesp.br/grupos/fibromialgia). The answers were grouped according to age, sex, years of schooling, and type of interest in the condition. **Results:** 92% of the responders were women and 62% had higher educational level. The worst results were observed in the "joint protection and energy conservation" domain, followed by the "medication in fibromyalgia" domain. The best results were recorded in the "exercises in fibromyalgia" domain. The answers differed significantly between sexes, and women achieved a higher percentage of correct answers. The female sex accounted for a statistically superior result in five statistical analyses (four questions and one domain). **Conclusions:** The study suggests the need for a strategic planning for an educational approach to fibromyalgia in Brazil.

Keywords: fibromyalgia, knowledge, education, internet.

[Rev Bras Reumatol 2011;51(1):7-19]

INTRODUCTION

Education on fibromyalgia is extremely important in treating the condition.[1,2,3] According to Cedraschi *et al*.,[4] the process of education on fibromyalgia should include information on the syndrome, classes about symptom self-management, physical exercise training,[5,6] discussions about the medicamentous treatment, and other cognitive and/or behavioral approaches.[7]

Bodenheimer *et al*.[8] have suggested that educational programs can reduce the use of medicaments, the number of medical visits,[9] and the length of hospital stay.[10]

Although several studies indicating the importance of education for treating the syndrome have been identified, knowledge about the efficacy of different educational strategies adopted is relatively small.

Studies on education about fibromyalgia usually assess clinical aspects, such as pain, mood, and quality of life; however, the patients' specific knowledge regarding the condition or the knowledge acquired with an educational program is not commonly assessed.[4] Nevertheless, that is an extremely important process, because the major objective of health education is the acquisition of specific knowledge about a disease to help patients manage and face their chronic conditions.[11]

Instruments capable of measuring specific knowledge can be useful in public health policies, because they are important

Submitted on 3/4/2010. Approved on 12/12/2010. We declare no conflict of interest. Ethics Committee # 0179/08.
Universidade Federal de São Paulo – Unifesp, São Paulo, SP, Brazil.
1. Post-graduate student of the Centro Cochrane do Brasil – Unifesp; MBA in Health Economics and Management
2. PhD, Professor of Rheumatology of Unifesp
3. PhD, Professor of the Universidade Federal do ABC – UFABC
4. PhD in Rheumatology, Professor of the Unifesp
5. Master's degree at the Centro Cochrane do Brasil; Researcher of the Centro Cochrane do Brasil
Correspondence to: Felipe Azevedo Moretti. Rua Pedro de Toledo, 598. Vila Clementino, São Paulo, SP, Brazil. CEP: 04039-001. E-mail: felipe.moretti@unifesp.br.

markers to help the specific needs of a certain group or program.[12]

With that in mind, a fibromyalgia knowledge questionnaire (FKQ),[13] developed at the Universidade Federal de São Paulo (Unifesp), was applied to identify possible educational strategies for a specific population: individuals looking for information about health on the Internet.

METHODS

Initially, a portal was launched on the Internet (www.unifesp.br/grupos/fibromialgia) to provide information about fibromyalgia and to attract individuals interested in the subject. An on-line version of the FKQ was made available with the following invitation: "test your knowledge on fibromyalgia". Before filling in the questionnaire, the individuals were instructed to provide personal data such as sex, age, educational level, and user type (patient, friend, relative, professional interested in scientific content). After completion, the individual was informed about his/her percentage of correct answers. Site users were also encouraged to send e-mail suggestions about their specific claims and needs regarding fibromyalgia.

In the analysis of results, the following FKQ domains were considered: "general knowledge about fibromyalgia" (questions 1 to 5); "medications in fibromyalgia" (questions 6 to 9); "exercises in fibromyalgia" (questions 10 to 13); and "joint protection and energy conservation" (questions 14 to 18).

Data were collected for six months (from November 2008 to April 2009) after study approval by the Committee on Ethics in Research of the Hospital São Paulo (protocol number 0179/08).

Data were stored and assessed by use of the statistical program SPSS, version 2004. The statistical analysis considered the sum of all correct answers. One point was attributed to every entirely correct answer, while a proportional score was given to a partially correct answer. The proportion of correct and wrong answers was also analyzed regarding the personal data provided (sex, age, educational level, and user type). The following statistical tests were used: chi-square, Mann-Whitney, Friedman, Fisher's exact, and binomial test.

RESULTS

In a six-month period, the site registered 4,224 accesses, with a mean of 704 accesses per month. Of the total accesses, 362 individuals completed the FKQ and 95 individuals sent e-mails with suggestions about specific needs relating to fibromyalgia.

Considering the individuals answering the FKQ, their mean age was 40 years, 92% were women and 8%, men. Regarding their educational level, 62% had higher education, 36% secondary education, and 2% had only elementary education. Of the 329 individuals providing their interest profile, 84% were patients, 9% reported being friends or relatives of patients with fibromyalgia, and 7% reported being professionals with scientific interest in the condition. Table 1 shows the frequency of correct answers.

The statistical analysis shows a greater frequency of correct answers among female participants. The greatest difference between both sexes was observed in question 11, relating to the importance of physical exercises for fibromyalgia (Table 2).

Table 1
Frequency of correct answers to the fibromyalgia knowledge questionnaire among the 362 individuals studied

Question numbers	Questions	Correct answers (%)
2	What are the major symptoms of fibromyalgia?	92
3	In addition to the above-cited symptoms, indicate one more that can be present	92
12	Which is the best way for a patient with fibromyalgia to exercise?	92
14	Which is the best way for you to conserve your energy?	90
10	What is the correct alternative regarding physical activity in the treatment of fibromyalgia?	89
15	Which are the other correct ways to conserve your energy?	88
5	What can happen to a patient due to fibromyalgia?	86
8	Which are the best associations when treating fibromyalgia?	86
13	Choose the two best methods for the rehabilitation of patients with fibromyalgia.	86
4	What is necessary for confirming the diagnosis of fibromyalgia?	82
11	How important is exercise training for patients with fibromyalgia?	82
18	Mark a correct alternative about fibromyalgia	82
7	Which are the medicines prescribed for treating fibromyalgia?	79
6	Which are the most indicated medicines for treating fibromyalgia?	78
1	Check two correct alternatives about the cause of fibromyalgia	69
9	What are the most common side effects of the medicines used for fibromyalgia?	61
16	What is the best way to protect your joints?	57
17	What is the best joint protection?	27

A significant difference regarding the educational level was observed in the answers to questions 4 (P = 0.008), 10 (P = 0.005), and 14 (P = 0.007), as shown in Table 3. No significant difference between the secondary and higher educational levels was found when analyzing the answers to questions 4 and 14 (P = 0.066 for question 4, and P = 0.079 for question 14, chi-square test). Regarding the answers to question 4, when comparing the elementary level with the two others, a significant difference was observed in the proportion "2 correct answers to 2" (P = 0.049, Fisher exact test). Regarding the answers to question 10, no significant difference was found between the secondary and elementary

Table 2
Significant differences in the amount of correct answers according to sex

Questions	Correct answers	Male		Female		P Value*
		n	%	n	%	
5. What can happen to a patient due to fibromyalgia?	0 correct answer in 2	5	17.9	17	5.1	0.022
	1 correct answer in 2	3	10.7	58	17.5	
	2 correct answers in 2	20	71.4	257	77.4	
	Total	**28**	**100.0**	**332**	**100.0**	
11. How important is exercise training for patients with fibromyalgia?	0 correct answer in 1	10	35.7	56	16.9	0.013
	1 correct answer in 1	18	64.3	276	83.1	
	Total	**28**	**100.0**	**332**	**100.0**	
13. Choose the two best methods for the rehabilitation of patients with fibromyalgia.	0 correct answer in 2	4	14.3	22	6.6	0.034
	1 correct answer in 2	7	70.0	40	71.4	
	2 correct answers in 2	17	94.4	270	97.8	
	Total	**28**	**100.0**	**332**	**100.0**	
14. Which is the best way for you to conserve your energy?	0 correct answer in 1	6	21.4	29	8.7	0.029
	1 correct answer in 1	22	78.6	303	91.3	
	Total	**28**	**100.0**	**332**	**100.0**	
15. Which are the other correct ways to conserve your energy?	0 correct answer in 2	4	14.3	13	4.8	0.32
	1 correct answer in 2	2	7.1	48	14.5	
	2 correct answers in 2	22	78.6	271	81.6	
	Total	**28**	**100.0**	**332**	**100.0**	

*Chi-square test, highest frequency of correct answers among women.

Table 3
Significant differences in the amount of correct answers according to educational level

Questions	Correct answers	Educational level					
		Elementary		Secondary		Higher	
		n	%	n	%	n	%
4. What is necessary for confirming the diagnosis of fibromyalgia?	0 correct answer in 2	2	25.0	7	6.1	7	3.5
	1 correct answer in 2	3	37.5	35	30.4	41	20.7
	2 correct answers in 2	3	37.5	73	63.5	150	75.7
	Total	8	100	115	100	198	100
10. What is the correct alternative regarding physical activity in the treatment of fibromyalgia?	0 correct answer in 1	2	25.0	18	15.6	11	5.5
	1 correct answer in 1	6	75.0	97	84.4	187	94.5
	Total	8	100	115	100	198	100
14. Which is the best way for you to conserve your energy?	0 correct answer in 1	3	37.5	15	13.0	14	7.1
	1 correct answer in 1	5	62.5	100	87.0	184	92.9
	Total	8	100	115	100	198	100

educational levels (P = 0.488, chi-square). However, a significant difference was observed when comparing the higher and the two other educational levels (P = 0.002, binomial test). Finally, in question 14, the frequency of correct answers in the elementary level was significantly lower than that in the two other levels (P = 0.036, Fisher exact test).

When comparing the frequency of correct answers in the four domains of the questionnaire, a significant difference was observed in the Friedman test for dependent samples (P = 0.001). A statistically significant difference was observed in all domains. Domain 3 (exercises in fibromyalgia) had a significantly higher frequency of correct answers than domain 1 (general knowledge about fibromyalgia), in which a higher number of correct answers was found as compared with domain 2 (medications in fibromyalgia) and domain 4 (joint protection and energy conservation).

When considering the variable sex and comparing the percentage of correct answers in each domain, a significant difference was found in domain 3, in which, the number of correct answers among females was significantly higher than that among males (P = 0.005, Mann-Whitney test). The other three domains showed no significant difference between the sexes.

When analyzing the e-mail messages, a systematic demand for more attention of the medical professionals in the contact with patients and in the search for information about the disease was observed. In addition, the generalized lack of knowledge on fibromyalgia in the society was explicitly emphasized.

Another relevant aspect was the complaint in the areas of legal and occupational medicine. The following topics were highlighted: the difficulty in working with more severe pain; the prejudice of coworkers, who do not understand or stigmatize the condition; and the difficulties faced in the procedures involving the Brazilian Institute of Social Security (*Instituto Nacional de Seguridade Social* - INSS).

Many patients have also reported the need for other treatment options, claiming that current options are ineffective or of little help. In addition, many have emphasized the lack of the following: information on the syndrome and on the possible access to alternative therapies; more skilled professionals; and decentralized and universal ways of action.

Find below some phrases sent via e-mail:

- Most people know nothing about fibromyalgia and have difficulty in understanding us, mainly in the work environment.
- Information about the disease should be made available, so that healthy people can believe us and patients can understand what they are going through.
- Sometimes people think we are faking the disease. The right for paid leave of absence would be of great help.
- More explanation about fibromyalgia and greater access to medicines are required.
- Many doctors do not recognize fibromyalgia as a syndrome. They seem to consider it a passing fad, and, in addition, they are not qualified to take care of their patients or to refer them to specialized professionals.
- The law should contemplate cases of fibromyalgia, because an individual with the condition often cannot work.
- Labor law addressing the legal rights for patients with fibromyalgia still lacks, and nobody pretends to feel pain.
- No rheumatologist could be found at any health center to conduct the treatment. Spaces for hydrogymnastics should be provided.
- Comprehensive health insurance coverage should be provided for alternative treatments, such as hydrotherapy, and other beneficial things, which are not always accessible due to high cost.
- Health professionals should be trained and our families instructed, because they do not believe that a patient with fibromyalgia can have so much pain in so many places at the same time.
- Professionals to take care of us and to make a precise and fast diagnosis are required. In addition, our labor rights need to be widened.
- Alternative programs to 'cure or relieve' fibromyalgia throughout Brazil are necessary. Some techniques are created by certain professionals at large centers, but they are not made available for the general population.
- Faster consultation scheduling with professionals skilled in fibromyalgia care is required.
- Medicines are expensive and out of the reach of those receiving one, two or three minimum wages. The Brazilian Unified Health Care System does not provide good medicines for fibromyalgia.
- Health insurance plans need to recognize fibromyalgia as a disease and not only as a condition due to stress, and should cover alternative treatments, which are currently very expensive and inaccessible.
- Information about new treatments, medications, and how to find an available and skilled professional to help us is required.

DISCUSSION

Some studies have already shown that the Internet, as a way to assess educational level and promote health, is a useful tool to patients with fibromyalgia.[11,12] Those studies have reported that site users, who search for specific information or interact via the Internet, have several benefits, such as better social relationship, clinical improvement, better self-management of the disease, better quality of life, and positive behavior changes.

Thus, Internet-based public health strategies should be encouraged, considering the Internet positive potential and other facilities, such as convenience, greater population reach, and integration of patients with fibromyalgia, without requiring physical presence.

The percentages of women and men (92% and 8%, respectively) responding to the questionnaire (11 women for every man) can be explained by the higher prevalence of the syndrome among women as compared with that among men. That proportion is usually reported as being 6 to 10 women for every man.[14]

Regarding the educational level of the sample studied (61.8% with complete higher education), the data found are consistent with those of surveys about the Brazilian population access to the Internet. The Brazilian Institute of Geography and Statistics - IBGE (*Instituto Brasileiro de Geografia e Estatística*) states that the percentage of individuals with access to the Internet in Brazil increases as their educational level increases. A 2005 survey about the years of schooling of Internet users showed the following percentages: [G1] no instruction or less than four years of schooling, 2.5% had access to the Internet; [G2] four to seven years of schooling, 10.1% had access to the Internet; [G3] eight to ten years of schooling, 22.6% had access to the Internet; [G4] 11 to 14 years of schooling, 42.8% had access to the Internet; [G5] at least 15 years of schooling, 76.2% had access to.[15]

Studies on the use of specific questionnaires capable of measuring the knowledge about fibromyalgia are rare. A literature review on the PubMed database, using the terms "fibromyalgia" and "knowledge", revealed 123 articles, but none of them assessed specifically the knowledge on the syndrome. The articles identified had assessed the perception about the disease and its impact on health from the patients' and their families' viewpoints.[16,17,18,19]

The only study using a questionnaire about knowledge on fibromyalgia was a master's thesis of the Unifesp, in which the author reported the lack of a questionnaire at that occasion to be applied in such cases and emphasized the importance of the FKQ construction and validation.[13]

The results obtained in the present study, in which the domains with the lowest indices of correct answers were "medications in fibromyalgia" and "joint protection and energy conservation", have suggested the creation of public strategies of education focusing those topics.

In Brazil, some studies have shown deficiencies in medical and pharmaceutical care, regarding the medicamentous management of patients.[20,21,22] According to the *World Health Organization Guide for Good Medical Prescription*,[23] after selecting the medicamentous treatment and writing the prescription, the physician should inform the patient on the following: short- (or long-) term objectives of the treatment instituted; how, when, and for how long a medicine should be taken; benefits and risks (drug-drug or drug-food interactions, adverse reactions, intoxications); and actions to be taken in the presence of adverse effects.

Arrais *et al*.[20] have suggested that the lack of a pharmacist in public and private health care units is a critical factor for implementing the rational use of medicines. Those authors have also emphasized the need for re-establishing the physician-patient and pharmacist-patient relationships as a fundamental aspect to improve the health care quality, in which personalization and humanization, as well as right to information, are basic components of the process.

Regarding the high frequency of mistakes in the "joint protection and energy conservation" domain, the following factors are involved: (a) small appreciation of that topic in the fibromyalgia context (unlike that which occurs in rheumatoid arthritis cases); (b) small amount of time designated by physicians and health care professionals for instructing their patients about their daily life activities; (c) poor phrasal formulation of the domain in the questionnaire.

One possible explanation to the highest index of correct answer to the questions involving symptoms of fibromyalgia and ways to exercise could be the patients' own perception of their symptoms. In addition, the most prevalent symptoms (present in the questions) are highlighted by patients, the media, and health care professionals, favoring the percentage of correct answers. Likewise, the broad dissemination of the importance of physical training can induce a higher preoccupation with that practice for fibromyalgia prevention.

The fact that women performed better in the test about knowledge on fibromyalgia can be explained by the higher prevalence of the condition among women.[14] This increases the search for information by women, thus enlarging their knowledge on the syndrome. Some authors have suggested that a 10% prevalence of fibromyalgia in men and 90% in women can be underestimated, and that the distinction between sexes

tends to be important.[24,25] Men tend to have complaints related to self-esteem, self-perception, and impact on social roles. In addition to the report of fewer symptoms, the impact regarding quality of life loss is smaller among men, who manage to preserve a better functional level. Men complain less of sleep disorders, fatigue, and generalized ache, which increases the risk of false-negative diagnoses, since they have mainly pauciarticular pain with less subjective characteristics.[26,27] Such elements suggest that educational programs disclosing the particularities of the sexes can increase the search for information, as well as the likelihood of correct diagnoses.

The results obtained in the analysis of the e-mails are in accordance with the data obtained by Kuahara,[28] who emphasizes the need for punctual actions, capable of minimizing biases against and stigmas attached to patients with fibromyalgia, in addition to strategies that promote better attention to the labor, medical, and familial aspects of those patients.

As practical implications, the authors suggest interventions in public health care and policies aimed at raising the consciousness and learning of patients with fibromyalgia, mainly in topics such as measures for joint protection and energy conservation. In addition, the FKQ should be disclosed and applied, as well as translated and validated in other languages, aiming at standardizing future studies focused on the knowledge of patients with fibromyalgia about their own disease. This would allow more solid conclusions that could support the decision making process and help health care professionals and patients in managing fibromyalgia.

REFERENCES

REFERÊNCIAS

1. Bennett RM. The Rational Management of Fibromyalgia Patients. Rheum Dis N Am 2002; 28:181-99.
2. Bodenheimer T, Loring K, Holman H, Grumbach K. Patient Self-management of chronic disease in Primary care. JAMA & Archives 2002; 288:2469-75.
3. Sandstrom M, Keefe FJ. Self-management of fibromyalgia: the role of formal coping skills training and physical exercise training programs. Arthritis Care Res 1998; 11:432-47.
4. Cedraschi C, Desmeules J, Rapiti E, Baumgartner E, Cohen P, Finckh A *et al*. Fibromyalgia: a randomised, controlled trial of a treatment programme based on self management. Ann Rheum Dis 2004; 63:290-6.
5. Marques AP, Matsutani LA, Ferreira EAG, Mendonça LLF. A fisioterapia no tratamento de pacientes com fibromialgia: uma revisão da literatura. Rev Bras Reumatol 2002; 42:42-8.
6. Marques AP. O que o fisioterapeuta pode fazer pelos fibromiálgicos? Revista CREFITO 2006; 3:25.
7. Lera S, Gewlman SM, López MJ, Abenoza M, Zorilla JG, Castro-Fornieles J. Salamero Multidisciplinary treatment of fibromyalgia: Does cognitive behavior therapy increase the response to treatment? Journal of Psychosomatic Research 2009; 67:433-41.
8. Bodenheimer T, Loring K, Holman H, Grumbach K. Patient Self-management of chronic disease in Primary care. JAMA & Archives 2002; 288:2469-75.
9. Oliveira MA, Muniz MT, Santos LA, Faresin SM, Fernandes ALG. Custo-efetividade de programa de educação para adultos asmáticos atendidos em hospital-escola de instituição pública. Jornal de Pneumologia 2002; 28:2.
10. De Oliveira MA, Faresin SM, Bruno VF, Bittencourt AR, Fernandes ALG. Evaluation of an educational programme for socially deprived asthma patients. Eur Respir J 1999; 14:1-7.
11. Murray E, Burns J, See Tai S, Lai R, Nazareth I. Interactive Health Communication Applications for people with chronic disease. 2005; *In:* The Cochrane Library, Issue 4.
12. Van Uden-Kraan CF, Drossaert CHC, Taal E, Seydel ER, Van de Laar MA. Self-Reported Differences in Empowerment Between Lurkers and Posters in Online Patient Support Groups. J Med Internet Res 2008; 10:e18.
13. Suda A. Criação e validação de um questionário de conhecimento em fibromialgia (KQF). Dissertação de mestrado. UNIFESP, 2003.
14. Provenza JR, Pollak DF, Martinez JE, Paiva ES, Helfenstein M, Heymann R *et al*. Projeto Diretrizes: Fibromialgia. Associação Médica Brasileira e Conselho Federal de Medicina, 2004. Disponível em http://www.unifesp.br/grupos/fibromialgia/fibromialgia.pdf. [Acesso em 04 de março de 2010].
15. Instituto Brasileiro de Geografia e Estatística. Diretório: Acesso a internet e posse de celular/internet. Disponível em http://www.ibge.gov.br/servidor_arquivos_est/. [Acesso em 10 de novembro de 2009].
16. Martinez JE, Cruz CG, Aranda C, Boulos FC, Lagoa LA. Disease perceptions of Brazilian fibromyalgia patients: do they resemble perceptions from other countries? Int J Rehabil Res 2003; 26:223-7.
17. Söderberg S, Strand M, Haapala M, Lundman B. Living with a woman with fibromyalgia from the perspective of the husband. Adv Nurs 2003; 42:143-50.

18. Van Ittersum MW, Van Wilgen CP, Hilberdink WK, Groothoff JW, Van Der Schans CP. Illness perception in patients with fibromyalgia. Patient Educ Couns 2009; 74:53-60.
19. Varni JW, Burwinkle TM, Limbers CA, Szer IS. The PedsQL as a patient-report outcome in children and adolescents with fibromyalgia: an analysis of OMERACT domains. Health Qual Live Outcomes 2007; 5:9.
20. Arrais PSD, Barreto ML, Coelho HLL. Aspectos dos processos de prescrição e dispensação de medicamentos na percepção do paciente: estudo de base populacional em Fortaleza, Ceará, Brasil. Cad Saúde Pública 2007; 23:927-37.
21. Cunha da Silva CD, Coelho HLL. Centro e informações sobre medicamentos: auxiliando a decisão terapêutica. Giornale Italiano di Farmacia Clinica 1999; 13:93-102.
22. Piccini RX, Victora CG. How well is hypertension managed in the community? A population-based survey in a Brazilian city. Cad Saúde Pública 1997; 13:595-600.
23. Organização Mundial da Saúde. Guia para boa prescrição médica. Porto Alegre: Editora Artmed; 1998.
24. Jorge LL, Tomikawa LCO, Juca SSH. Efeito de um programa de reabilitação multidisciplinar para homens portadores de fibromialgia: estudo aleatorizado controlado. Acta Fisiatr 2007; 14:196-203.
25. Yunus MB, Inanici F, Aldag JC, Mangold RF. Fibromyalgia in men: comparison of clinical features with women. J Rheumatol 2000; 27:485-90.
26. Buskila D, Neumann L, Alhoashle A, Abu-Shakra M. Fibromyalgia syndrome in men. Semin Arthritis Rheum 2000; 30:47-51.
27. Yunus MB. Gender differences in fibromyalgia and other related syndromes. J Gend Specif Med 2002; 5:42-7.
28. Kuahara MV. Fibromyalgia: the perception of the syndrome by women, an qualitative approach. Tese de Doutorado. UNIFESP, 2004.