

Education in fibromyalgia. A systematic review.

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Abstract

Fibromyalgia is a complex condition estimated to affect 2% to 5% of the US adult population and 0.5% to 5% of other Western populations that is characterized by chronic widespread musculoskeletal pain and multiple other symptoms, including fatigue, sleep disturbances, cognitive dysfunction, stiffness, and depressive episodes. Evidence-based guidelines suggest that fibromyalgia is typically managed with multidisciplinary therapies involving medication, cognitive behavioral therapy, education, and exercise.

A data search was conducted in March 2014 using the PubMed and MEDLINE databases. The search strategy was based on Mesh terms “fibromyalgia” and “education”:
("Fibromyalgia"[Mesh]) AND "Education"[Mesh]

The search for studies resulted in a total of 45 references. After screening phase based on the selection criteria, 22 studies remained.

Most of the studies we have found use education inside a treatment program or multidisciplinary program.

Finally, although we know patient information needs and receptivity to information vary across the course of an illness there has short research about FM specific information needs. However we know prior to diagnosis, people were interested in learning more about symptoms and future consequences of the disease. After diagnosis, they were more interested in learning about treatments, impacts on life, coping and alternative sources of support.

1. Introduction

Fibromyalgia is a complex condition estimated to affect 2% to 5% of the US adult population and 0.5% to 5% of other Western populations that is characterized by chronic widespread musculoskeletal pain and multiple other symptoms, including fatigue, sleep disturbances, cognitive dysfunction, stiffness, and depressive episodes. Fibromyalgia may coexist and/or overlap with other conditions that may involve central sensitivity, including chronic fatigue

syndrome, irritable bowel syndrome, irritable bladder syndrome or interstitial cystitis, and temporomandibular disorder. Symptoms in fibromyalgia tend to vary among individuals, which suggests heterogeneity in the underlying mechanisms of fibromyalgia and the possibility of subgroups of patients with fibromyalgia.^{1,2}

The pathophysiology of fibromyalgia remains uncertain but is believed to be partly the result of central systems affecting afferent processing as well as impaired endogenous pain-inhibitory systems. Abnormal central nociceptive processing may contribute to fibromyalgia, producing heightened responses to various noxious stimuli with resulting mechanical hyperalgesia. Fibromyalgia remains a clinical diagnosis. There has been a recent paradigm shift away from requiring 11 or more out of 18 tender points and instead focusing on the presence of chronic widespread pain as well as symptoms of fatigue, unrefreshed sleep, and other somatic complaints.¹

Although there is no known cure for fibromyalgia, multidisciplinary team efforts using combined treatment approaches, including patient education, aerobic exercise, cognitive behavioral therapy, and pharmacologic therapies may improve symptoms as well as function of patients with fibromyalgia. Nonpharmacologic approaches appeared to be more effective than pharmacologic treatments and the combination of cognitive behavioral therapy and exercise training is the most effective nonpharmacologic intervention for patients with fibromyalgia.²

As the central sensitization mechanism is the most likely explanation for fibromyalgia symptoms, based on the belief that recovery can be fostered if patients understand the nature of their problems better, it seems important to educate patients about this neurophysiological background of their illness. Patient education, defined as “any set of planned educational activities designed to improve patients’ health behaviors and/or health status”, is specifically aimed at informing and reassuring patients and at restructuring their perceptions of illness.

In FM patients education alone, in the form of small-group discussions, oral theoretical information, practical sessions and cognitive behavioral treatment, has shown to enhance self-efficacy and health perception. Combining patient education with, for example, swimming pool exercises or aerobic fitness has shown beneficial effects on endurance, grip strength, pain, social functioning, psychological distress and health status in patients with FM.³

The diagnosis of FMS often results in confusion and increased uncertainty among patients. To decrease uncertainty, patients search for information and develop or adjust illness beliefs.

Once a diagnosis of fibromyalgia is considered likely it is important to explain the condition fully to the patient. Having suffered from unexplained widespread chronic pain for months or often years, the patient is often reassured to know that she is not suffering from a life-

threatening condition and that finally someone is going to help her manage the disorder. A patient's understanding and cooperation is important in treating most disorders. In fibromyalgia, it is particularly important since the management depends as much on the patient learning to cope with the disorder as on pharmacotherapy. This can only be achieved if the patient is fully educated concerning the condition.⁴

Evidence-based guidelines suggest that fibromyalgia is typically managed with multidisciplinary therapies involving medication, cognitive behavioral therapy, education, and exercise.⁵

Most experts agree that an educational or psychoeducational treatment component is useful if not necessary when treating FM. Such educational programs target increasing understanding of the complex nature of the interactions between neurobiological processes, behaviors such as sleep and/or activity levels, and symptoms. These programs are focused to allay the stigma often attached to FM and similar disorders. Goldenberg⁶ has recently set out recommendations regarding education that seem well founded. He points out that: "When educating patients, a core set of information should be provided that includes a detailed discussion of potential pathophysiological mechanisms in the context of the biopsychological model. The clinician must dispel the notion that the absence of organic disease means that the symptoms are psychogenic".

The nursing research model, which was informed by Nola Pender's (1987) cognitive-perceptual Health Promotion Model, proposes that contextual and attitudinal factors influence health-promoting behaviors and in turn quality of life for persons with chronic disabling conditions. Consistent with this model, the intervention supported women with FMS to build self-efficacy for change by addressing the barriers, resources, and skills necessary to change their health behaviors. The use of goal attainment scaling to facilitate and assess individualized change in a wellness intervention for women with fibromyalgia syndrome.⁷

2. Methods

A data search was conducted in March 2014 using the PubMed and MEDLINE databases. The search strategy was based on Mesh terms "fibromyalgia" and "education": ("Fibromyalgia"[Mesh]) AND "Education"[Mesh]

The studies searched were verified for publication in English peer-reviewed journals.

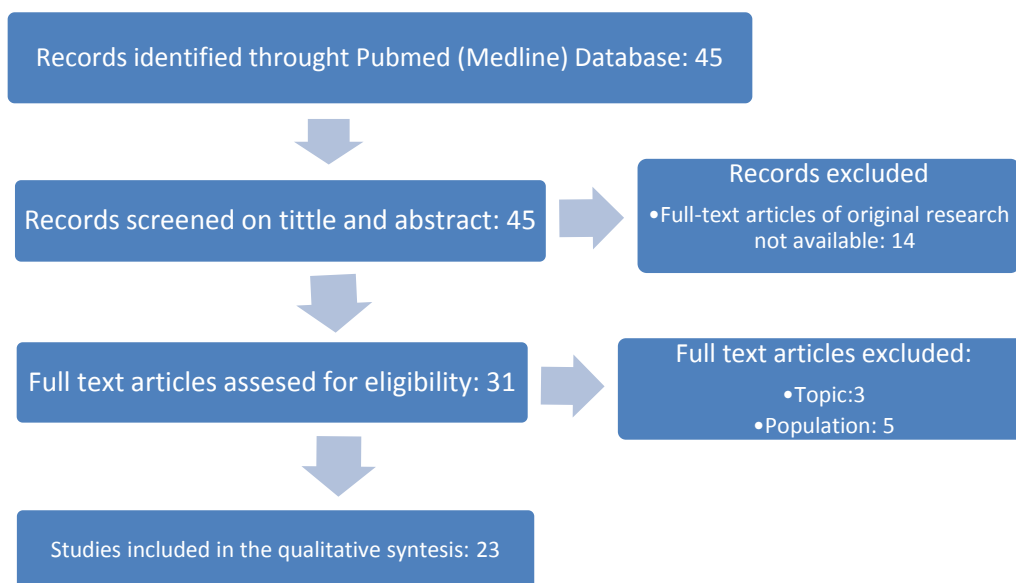
In order to be included, each study had to meet the following inclusion criteria: (1) the population consisted of people and not animals; (2) patients were diagnosed with FM; (3) Spanish and English articles were allowed; (4) full-text articles of original research had to be

available; and (5) to be published in the last five years in english or spanish. Whenever one of the five criteria was not fulfilled, the article was excluded.

This work is a narrative review focusing on the educational programs and their effects on fibromyalgia symptoms.

3. Results

The search for studies resulted in a total of 45 references. After screening phase based on the selection criteria, 22 studies remained. The screening process is presented in the Figure.



In order to structurally present the relevant data from the articles an evidence table was created (Table 1). The following items were systematically extracted from every article: authors, year of publication, patient characteristics, design and results.

Table 1

Authors	Year	Design	Sample	Intervention
Camerini L, Camerini AL, Schulz PJ. ⁸	2013	Cross sectional study	209 FM patients	Completed an online questionnaire to assess patients' use of the website, Health knowledge, selfmanagement behavior, and health outcomes.
Kim CH, Luedtke CA, Vincent A, Thompson JM, Oh TH. ⁹	2012	Cohort	Subjects (n = 477) with FM	FM Treatment program. Cognitive behavioural therapy, education and selfmanagement
Oh TH, Hoskin TL, Luedtke CA, Weingarten TN, Vincent A, Kim CH, Thompson JM. ²	2012	Cohort	A total of 536 patients with a confirmed diagnosis of FM	Brief interdisciplinary fibromyalgia treatment program. (education, self-management, physical and occupational therapy, which focused on cognitive behavioral techniques. They were given an opportunity to discuss how fibromyalgia affected their lives and to ask questions.)
Van Ittersum MW, van Wilgen CP, Groothoff JW, van der Schans CP. ³	2011	Cohort		
Camerini L, Schulz PJ, Nakamoto K. ¹⁰	2012	Cross sectional study	209 FM patients	Completed an online questionnaire to assess how health knowledge and empowerment affects selfmanagement behavior, and health

				outcomes.
Hannes B, Hauge MI, Kjekken I, Hagen KB. ¹¹	2011	Cualitative	8 patients with FM and 8 with Rheumatoid Arthritis.	Self-management programmes
Chen AT. ¹²	2012	Descriptive survey	190 FM patients	---
Camerini L, Schulz PJ. ¹³	2012	Pre-post design	165 FM patients	Web-based eHealth intervention
Hannes B, Mowinckel P, Kjekken I, Hagen KB. ¹⁴	2012	RCT	150 FM patients. (Experimental group n =75 or waiting list n=75).	Self-management program. This model contains six interrelated concepts: The participant's learning abilities, pedagogical framework(s), teaching goals, contents, learning/teaching methods and evaluation.
Castel A, Fontova R, Montull S, Periñán R, Poveda MJ, Miralles I, et al. ¹⁵	2013	RCT	155 women with FM	Conventional pharmacologic treatment or multidisciplinary treatment (information about FM, theory of pain perception, cognitive restructuring skills training, Cognitive Behavioural Therapy, Schultz autogenic training and physical therapy)
Jones KD, Sherman CA, Mist SD, Carson JW, Bennett RM, Li F. ¹⁶	2012	RCT	100 FM patients (tai chi n=51 and education n=47)	Yang-style Tai chi intervention (twice weekly for 12 weeks), and education intervention (included orientation, basic FM facts, healthy eating, and psychoeducation about FM.)
Luciano JV, Martínez N, Peñarubia-María MT, Fernández-Vergel R, García-Campayo J, Verduras C, et al. ¹⁷	2011	RCT	108 FM patients assigned to the intervention and 108 to usual care	Psychoeducational Treatment Program with 5 sessions of education and 4 sessions of autogenic relaxation
Wang C, Schmid CH, Ronés R, Kalish R, Yinh J, Goldenberg DL, et al. ⁵	2010	RCT	66 FM patients, the 33 in the tai chi group	Classic Yang-style tai chi as compared with a control intervention consisting of wellness education and stretching.
Stuifbergen AK, Blozis SA, Becker H, Phillips L, Timmerman G, Kullberg V, Taxis C, Morrison J. ¹⁸	2010	RCT	187 women (98 treatment, 89 control) with FM	Two-phase Lifestyle Counts intervention programme included Lifestyle change classes. Attention-control group was offered contact in classes on general disease-related information and health education topics.
Fontaine KR, Conn L, Clauw DJ. ¹⁹	2010	RCT	84 minimally active adults with FM	Lifestyle physical activity or a FM education control group
Becker H, Stuifbergen A, Taxis C, Beal CC, Pierini DM. ⁷	2009	RCT	92 women, age 20 to 75 years, with FM for at least 6 months.	Goal attainment scaling in a wellness intervention
Oh TH, Stueve MH, Hoskin TL, Luedtke CA, Vincent A, Moder KG, Thompson JM. ²⁰		Clinical Trial	521 participants with FM	A 1 1/2-day interdisciplinary FM treatment program
Arnold LM, Clauw DJ, Dunegan LJ, Turk DC; ¹	2012	Review		---
Wilson B, Spencer H, Kortebein P. ²¹	2012	Review		---
de Miquel CA, Campayo J, Flórez MT, Arguelles JM, Tarrío EB, Montoya MG, et al. ²²	2010	Review		---
Nijs J, Mannerkorpi K, Descheemaeker F, Van Houdenhove ²³	2010	Review		---
Hassett AL, Gevirtz RN. ²⁴	2009	Review		---
Suda AL, Jennings F, Bueno VC, Natour J. ²⁵	2012	Validation FM Knowledge Questionnaire		Fifteen patients and 12 healthcare professionals in the focus groups.

Most of the studies we have found use education inside a treatment program or multidisciplinary program. The results of Kim et al.⁹ show significant improvement in the Fibromyalgia Impact Questionnaire (FIQ) total score and the SF-36 through this treatment program including cognitive behavioural therapy, education and Self-management. Similar

results were found by Oh et al.²⁰ with a brief interdisciplinary FM treatment program, where all FIQ subscales except depression and SF-36 scores, except general health perception and role emotional, improved significantly. This treatment produced greater benefit in patients with younger age, more years of education (with college or graduate degree), higher baseline FIQ depression score, lower tender point count, and absent abuse history². On the other hand, Hammes et al.¹⁴ show in their study that in patients with FM, the Self-management program had no effect on psychological distress, functional and symptomatic consequences and self-efficacy, except for a small short-term effect on skills and behavior that are important for managing and participating in health care. Other multidisciplinary FM treatment adapted for individuals with low educational levels was carried out by Castel et al.¹⁵ In this study the treatment was effective in reducing key symptoms of FM. Some improvements were maintained 1 year after completing the multidisciplinary treatment.

The nine sessions Psychoeducational Treatment Program carried out by Luciano et al.¹⁷ improved in physical impairment, days not feeling well, pain, general fatigue, morning fatigue, stiffness, anxiety, and depression (medium effect size in most cases). Moreover the patients who responded to the intervention reported less trait anxiety at baseline than nonresponders.

Other papers use education as the intervention in the control group. This is the case in Stuifbergen et al.¹⁸ study in which both groups (Lifestyle Counts intervention group and education group) improved significantly over time on the measures of self-efficacy, health behaviours, FM impact and quality of life. In the study of Fontaine et al.¹⁹, compared to FM education control group, the lifestyle physical activity group reported significantly less perceived functional deficits and less pain but there were no differences between the groups on the six-minute walk test, fatigue, depression, body mass index, or tenderness.

Wang et al.⁵ and Jones et al.¹⁶ use education in the control group versus a Tai chi intervention. Both of them obtained similar results so as Tai chi condition compared with the education condition demonstrated clinically and statistically significant improvements in FIQ scores and quality of life

The Goal Attainment Scaling implemented by Becker et al.⁷ can effectively capture behavioral changes associated with a holistic health promotion intervention.

Written education about pain neurophysiology is, as Van Ittersum et al.³, inadequate toward changing illness perceptions, catastrophizing or perceived health status of participants with FM; education should be incorporated into a broader multidisciplinary self-management program.

Only one qualitative study in the last five years has been found. Hamnes et al. indicated that identifying expectations prior to a Self-management program provides important information which has implications for the programme's implementation. Additional themes, such as acceptance of the illness and management of work, should also be included in the programmes and they should focus more on sharing experience.

Finally we found some studies about an Internet-based patient education intervention for fibromyalgia patients. This studies empirically confirmed that the adoption of a participatory approach to the design of eHealth interventions and the use of personalized contents enhance the overall effectiveness of systems, and the presence of interactive elements in eHealth intervention did not affect knowledge, did not affect patient empowerment, and did not improve the health outcome of perceived fibromyalgia impact. In contrast to other studies, these studies did not find beneficial effects of functional interactivity, however, knowledge and two dimensions of empowerment (meaning and self-determination) did affect health outcomes.^{8,10,13}

4. Discussion and conclusion

An acceptable explanation for symptoms experienced by the patient is required to accept the fact that they have a debilitating illness. However, many patients with FM have maladaptive illness beliefs, cognition, and behaviors that preclude successful rehabilitation. Poor understanding of pain may lead to the acquisition of maladaptive attitudes and behavior in relation to pain. Furthermore, it is known that more adequate pain beliefs lead to increased confidence, which, in turn, leads to increased activity levels. Thus, patients with FMS must develop a degree of knowledge before they can learn how to cope with their illness. Besides educating patients with FMS about the nature of their symptoms and illness, education often is used to introduce and implement various other treatment options such as activity management, stress management, and exercise therapy.

While more research is clearly needed, it appears that education will be most effective in multi-modal interventions. The research, as well as our clinical experience, indicates that the addition of education and a behavioral or cognitive-behavioral component to FM treatment protocols is warranted. People suffering from chronic diseases constantly live in a peculiar situation. They are faced with the problem of keeping a balance between the need to adhere to a treatment and the need to live their everyday life and activities as normally as possible. In other words, they must learn how to self-manage their condition by increasing their knowledge through information, and empowerment through the provision of social support.⁸

Education plays an essential role in fibromyalgia management and can be integrated into a treatment plan after diagnosis and continued throughout follow-up. Time for patient education is often restricted in busy practices, making it important to plan and make optimal use of existing

resources (books, Internet, community). Organizing small group lectures for individuals with FM and their family members and using clinical support staff to provide supplemental education are also efficient ways to provide FM information. Education should include management of expectations early in the course of therapy. Setting basic expectations for how the clinician and patient will work together can help to establish a productive and efficient partnership and minimize frustration.¹

Continued education after diagnosis is a key objective of this management framework. As part of this ongoing education, the importance of adherence to all aspects of the treatment program should be highlighted, and non adherence with pharmacological or non pharmacological therapies should be addressed, particularly for medications that do not produce an instant, noticeable effect on symptoms. Management of patients with FM should be approached by implementation of a chronic care framework based on core principles of education, goal setting, multidisciplinary management, routine monitoring, and outcomes assessment. Follow-up should involve specific resources that help health care professionals educate patients and their families to engage in self-management and carry out ongoing assessment to track disease status over time.¹

Although we know patient information needs and receptivity to information vary across the course of an illness there has short research about FM specific information needs. However we know prior to diagnosis, people were interested in learning more about symptoms and future consequences of the disease. After diagnosis, they were more interested in learning about treatments, impacts on life, coping and alternative sources of support.¹²

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