

Patients' and professionals' views on managing fibromyalgia

Erica Briones-Vozmediano^{1,2}, Carmen Vives-Cases PhD MPH^{1,2,3}, Elena Ronda-Pérez MD PhD MPH^{1,2,3},
Diana Gil-González PhD MPH^{1,2,3,4}

E Briones-Vozmediano, C Vives-Cases, E Ronda-Pérez, D Gil-González. Patients' and professionals' views on managing fibromyalgia. *Pain Res Manag* 2013;18(1):19-24.

BACKGROUND: Managing fibromyalgia is a challenge for both health care systems and the professionals caring for these patients, due, in part, to the fact that the etiology of this disease is unknown, its symptoms are not specific and there is no standardized treatment.

OBJECTIVE: The present study examines three aspects of fibromyalgia management, namely diagnostic approach, therapeutic management and the health professional-patient relationship, to explore specific areas of the health care process that professionals and patients may consider unsatisfactory.

METHODS: A qualitative study involving semistructured interviews with 12 fibromyalgia patients and nine health professionals was performed.

RESULTS: The most commonly recurring theme was the dissatisfaction of both patients and professionals with the management process as a whole. Both groups expressed dissatisfaction with the delay in reaching a diagnosis and obtaining effective treatment. Patients reported the need for greater moral support from professionals, whereas the latter often felt frustrated and of little help to patients. Patients and professionals agreed on one point: the uncertainty surrounding the management of fibromyalgia and, especially, its etiology.

CONCLUSION: The present study contributes to a better understanding regarding why current management of fibromyalgia is neither effective nor satisfactory. It also provides insight into how health professionals can support fibromyalgia patients to achieve beneficial results. Health care services should offer greater support for these patients in the form of specific resources such as fibromyalgia clinics and health professionals with increased awareness of the disease.

Key Words: *Fibromyalgia; Pain management; Patient care; Therapy; Qualitative research*

Managing chronic illnesses is a challenge for health care systems and the professionals caring for these patients (1,2). Chronic illnesses are characterized by certain conditions that are difficult to control and needs that vary from one patient to another, thus making diagnosis, treatment and the doctor-patient relationship difficult (3-8). Fibromyalgia is a chronic disease that affects approximately 5% of the general population, mainly women (9-11). The main symptom is generalized musculoskeletal pain associated with fatigue, sleep disorders, morning stiffness and depression (12-14).

The nonspecific symptomatology of fibromyalgia, together with the absence of radiological, analytical and anatomic-pathological findings, makes management of the disease difficult. In addition, treatment is provided according to the symptoms experienced by the patient and is not standardized (15-17). Disease management is a system of coordinated health care interventions aimed at improving patient care and quality of life, as well as supporting the professional-patient relationship (18,19). The right diagnostic approach leads to greater therapeutic success, and both depend to a great extent on a good health professional-patient relationship (20,21).

¹Department of Community Nursing, Preventive Medicine & Public Health and History of Science; ²Public Health Research Group of Alicante University; ³Centre for Biomedical Research on Epidemiology and Public Health; ⁴Observatory of Public Policies and Health, University of Alicante, Alicante, Spain

Correspondence: Ms Erica Briones-Vozmediano, Department of Community Nursing, Preventive Medicine & Public Health and History of Science, University of Alicante, San Vicente del Raspeig, 03690, PO Box 99, E-03080, Alicante, Spain. Telephone 34-965-903-832, fax 34-965-903-964, e-mail erica.briones@ua.es

Le point de vue des patients et des professionnels sur la prise en charge de la fibromyalgie

HISTORIQUE : La prise en charge de la fibromyalgie est complexe, à la fois pour les systèmes de santé et les professionnels qui soignent les patients, en partie parce qu'on ne connaît pas l'étiologie de la maladie, que ses symptômes ne sont pas spécifiques et qu'il n'y a pas de traitement normalisé.

OBJECTIF : La présente étude portait sur trois aspects de la prise en charge de la fibromyalgie, soit l'approche diagnostique, la prise en charge thérapeutique et la relation entre le professionnel de la santé et le patient, afin d'explorer des secteurs précis du processus de santé que les professionnels et les patients peuvent trouver insatisfaisants.

MÉTHODOLOGIE : La présente étude qualitative était constituée d'entrevues semi-structurées auprès de 12 patients atteints de fibromyalgie et de neuf professionnels de la santé.

RÉSULTATS : Le thème le plus récurrent était l'insatisfaction des patients et des professionnels à l'égard de l'ensemble du processus de prise en charge. Les deux groupes exprimaient leur insatisfaction quant au délai de diagnostic et à l'obtention d'un traitement efficace. Les patients ont déclaré le besoin d'un meilleur soutien moral de la part des professionnels, tandis que ceux-ci se sentaient souvent frustrés et peu utiles aux patients. Les patients et les professionnels s'entendaient sur un point : l'incertitude entourant la prise en charge de la fibromyalgie et, surtout, son étiologie.

CONCLUSION : La présente étude contribue à mieux comprendre pourquoi la prise en charge de la fibromyalgie n'est ni efficace, ni satisfaisante. Elle donne également un aperçu de la manière dont les professionnels de la santé peuvent soutenir les patients fibromyalgiques afin d'obtenir des résultats bénéfiques. Les services de santé devraient offrir un plus grand soutien à ces patients, sous forme de ressources précises comme les cliniques de fibromyalgie et les professionnels de la santé qui connaissent mieux la maladie.

Diagnosis of fibromyalgia usually has a positive impact on patients, mainly because it means the disease becomes legitimized (22-24). Thus, giving the disease a diagnostic label helps the patient to cope and lessens stigmatization (25). Nevertheless, some authors claim that being diagnosed with fibromyalgia may have a negative effect on the patient's identity and self-esteem (26). What is clear, however, is that patients describe their search for a diagnosis, which usually involves long delays and numerous consultations with a variety of specialists, as frustrating and unsatisfactory (23,25,27).

Studies also describe feelings of dissatisfaction with the drugs prescribed because patients notice very little improvement in their symptoms (28,29). Some recent studies report that one of the options patients most highly value are nonpharmacological treatments; however, these also have some drawbacks because they are usually very expensive, it is necessary to persevere with treatment and the benefits are only apparent in the long term (27).

The relationships between fibromyalgia patients and health professionals tend to be difficult (25,30). Patients described being understood by the professionals caring for them as a necessity (31). However, they

TABLE 1
Professionals' profiles

Code	Sex	Professional profile	Institution
Professional 1	Female	General practitioner	Nongovernmental organization
Professional 2	Male	Occupational health doctor	Hospital
Professional 3	Male	Physiotherapist	Health care centre
Professional 4	Male	Rheumatologist	Hospital
Professional 5	Male	Occupational health doctor	Social security disability assessment team
Professional 6	Male	Occupational health doctor	Social security disability assessment team
Professional 7	Male	Occupational health doctor	Social security disability assessment team
Professional 8	Female	Psychologist	FM Patients Association
Professional 9	Female	Psychiatrist	FM Patients Association

FM Fibromyalgia

frequently complained of a lack of understanding and support among professionals (26,32,33). Furthermore, when there is no agreement on the diagnosis, causes or treatment, patients may become so frustrated that they do not even complete the therapy prescribed (34). There are very few studies investigating the different aspects of fibromyalgia management from a health professional's perspective (35-37). Those that do exist describe the uncertainty that professionals experience when dealing with this disease due to the lack of knowledge concerning its etiology and treatment. In these studies, professionals describe their encounters with patients as problematic because they often feel that their professionalism and explanations are questioned by the latter. Even so, they recognize that taking an interest in patients, showing empathy and communicating with them is beneficial.

To date, the opinions of professionals and patients concerning the care provided for fibromyalgia have only been compared by collecting information from discussion groups, which included patients with other chronic pathologies (2). These fibromyalgia patients considered the care provided by doctors and health care services to be deficient, especially with regard to integrated, humane, respectful care, clear relevant information and continuity in the follow-up. In turn, doctors considered that a great deal of the effort they put into caring for these patients was wasted and believed it was important to reconsider their clinical obligations and relationship with the patients.

To date, studies on fibromyalgia have mainly focused on the diagnostic approach and therapeutic management or on the health professional-patient relationship (15,26,32,38). However, these three aspects have not been analyzed together in the scientific literature. Moreover, the views of fibromyalgia patients and health professionals responsible for their care concerning management of this disease are not known. Therefore, the present study aimed to explore the three aspects of the clinical management of fibromyalgia (diagnostic approach, therapeutic management and health professional-patient relationship) from two different points of view – that of the professionals and that of the patients – to identify specific areas of the health care process that are deficient or unsatisfactory.

METHODS

Design

The present study used a qualitative methodology, and the information was collected by means of semistructured personal interviews. Personal interviews are useful for gaining a deeper understanding of the aspects related to managing chronic illness from the point of view of the patients and professionals involved (39-41). The present study was part of a wider ongoing research project involving the personal experiences of fibromyalgia patients and the professionals responsible for their care.

TABLE 2
Patients' profiles

Code	Sex	Age, years	Profession*	Marital status	Number of children
Patient 1	Female	61	Inactive (orange-packing factory worker)	Married	One boy, one girl
Patient 2	Male	42	Labourer	Divorced	Two boys
Patient 3	Female	52	Unfit for work	Divorced	One boy
Patient 4	Female	53	Inactive (waitress in a family-owned bar)	Married	Two boys, one girl
Patient 5	Male	54	Sick leave (teacher)	Married	One boy
Patient 6	Female	33	Inactive (cook)	Married	One boy
Patient 7	Female	52	Cleaner	Married	One boy
Patient 8	Female	44	Administrative assistant	Married	Two girls
Patient 9	Female	38	Hairdresser	Lives with partner	None
Patient 10	Female	29	Call centre operator	Lives with partner	None
Patient 11	Male	48	Inactive (truck driver)	Married	One boy, one girl
Patient 12	Female	45	Primary school teacher	Married	Two boys

*In case of current inactivity, the former profession is indicated in parentheses

Participants

A total of 21 interviews were conducted (nine with health professionals and 12 with fibromyalgia patients). The professionals interviewed were from a variety of backgrounds (general practitioners, rheumatologists, psychiatrists, psychologists, physiotherapists and occupational health doctors) but were all involved in treating fibromyalgia patients (Table 1). The health professional study participants were between 40 and 55 years of age, and all worked for the Spanish National Health Service. In the patient sample, nine were women and three were men (age range 29 to 61 years). Sex (mainly women) and age (>40 years of age) were important factors because the highest prevalence of fibromyalgia was found in these groups (42) (Table 2).

Data collection

The first strategy used to recruit participants was to contact patient associations in a region in the east of Spain (Region of Valencia). Second, professionals were recruited using a snowballing technique, via a general practitioner and physiotherapist who facilitated contact with other colleagues. This resulted in a convenience sample. The informer selection process was performed according to pragmatic and feasibility criteria, given the difficulties in accessing the patients due to the consequences of the disease (43).

The interview guide included a series of topics to be discussed during the interview. A list of lines of inquiry was produced to provide guidelines for the interactions with interviewees and for the subsequent organization of the information. There were no textual formulations, predetermined sequential order or answer options. The interview guide was produced after reviewing the literature and considering the experience and knowledge of the research team.

The interview for professionals was divided into two sections: an opening question concerning the professional skills involved in their particular speciality for the care of fibromyalgia patients; and a closing question about their general evaluation and the possibility of improving management of the disease. The first section dealt with their experience with patients and the problems encountered, and the second with the interventions performed, type of treatment and degree of patient satisfaction with the interventions. The interview for fibromyalgia patients comprised three sections: one regarding social relations, one regarding factors aggravating the disease and one regarding demands for public action (institutions, professionals and social networks) to improve their situation. This interview also included an opening question to the patients regarding the repercussion of being diagnosed with fibromyalgia on their daily lives and

ended with a question regarding proposals to improve their quality of life.

The interviews were conducted by the first author, together with one other field worker from a team specialized in conducting qualitative studies, and lasted for approximately 1 h. The patients were interviewed in their homes and the professionals in their surgeries (offices). The interviews were conducted until data saturation was reached (43). In keeping with the Declaration of Helsinki and Belmont Report principles, the investigators explained the purpose and procedure of the study, provided an opportunity to ask questions and obtained written informed consent from each participant before data collection. Ethics approval was sought from the Medical Ethics Committee of the University of Alicante, which advised that it was not required for the present study.

Data analysis

The interviews were taped and then transcribed verbatim after a control procedure was performed to validate the information, relevance and sound quality. The contents of the interviews were divided into three theoretical categories that emerged from the data: diagnostic approach, therapeutic management and health professional-patient relationship. Using these main theoretical categories, the subtopics described in the Results section were identified. Each of the authors examined all the interviews independently, and together they compared and combined their analyses. The discourse analysis strategy used was descriptive and interpretive, based on inductive reasoning (39).

RESULTS

Diagnostic approach

Health professionals: In the interviews with physicians, it was determined that one of the main difficulties in reaching a diagnosis is that there are no objective diagnostic tests for fibromyalgia. This means that professionals lack the certainty they would have in the case of diseases with clearer diagnostic criteria.

The problem is that there is no objective test to diagnose these patients. I don't have a test that enables me to say: "this patient has fibromyalgia or doesn't have fibromyalgia". (Professional 4)

All of the professionals interviewed, irrespective of their speciality, stated that diagnosis was reached by elimination. Based on the patient's medical history, physicians perform a physical examination and request various complementary tests to rule out other pathologies, mainly rheumatological or psychiatric disorders. Although most agreed that they made a clinical diagnosis, they did not appear to be able to reach agreement as to which complementary tests should be performed in all cases.

The fact that the etiology of fibromyalgia is unknown makes it difficult for physicians to diagnose the disease and, consequently, to treat patients.

Patients: Due to these difficulties, patients must undergo a long process of consultations with different specialists and an extensive battery of eliminatory tests before being diagnosed. All of the patients participating in the study first consulted their general practitioner and were finally referred to a specialist in rheumatology who confirmed the diagnosis. This disease may take years to be diagnosed, during which time the patient continues to experience a number of symptoms.

Because I'd spent too many years going from one doctor to another, wandering around hospitals, going from pillar to post and nobody could tell me what was wrong with me. (Patient 1)

Health professionals and patients: Professionals and patients agreed that reaching a diagnosis was the turning point for the latter because of the need to give credibility to their symptoms and feel legitimized.

The fact that they tell you that you have a problem that's not just to do with your nerves and that there's something wrong physically... Just that gives you a certain sense of relief. (Professional 1)

Well, my reaction was that I was glad there was something wrong, that I hadn't invented it because up to that moment it was all psychological, it was all in my mind. (Patient 11)

Therapeutic management

Health professionals: The interviews with professionals illustrated that the lack of a known origin of the disease was reflected in the treatment prescribed. As they pointed out, treatment must be individualized because there is no effective, specific treatment for fibromyalgia and the disease is defined by a variety of symptoms that depend on the patient in question. Even so, therapeutic success is not guaranteed and professionals usually need to attempt various combinations.

Because you don't really know what's happening there. The etiology of the disease is not really known and you have few means of knowing what you're doing. You're treating the pain and you don't know why there is no response. (Professional 4)

Professionals questioned the effectiveness of treatments based on antidepressants and tranquillizers which, although they may help to treat certain problems, such as insomnia, created a dependency that was difficult to overcome. They considered that treatments to alleviate the pain were more useful but that these were also insufficient.

They are in pain, you give them something for the pain and: "it doesn't do me any good... it relieved the pain a little but the pain has come back", "you gave me this and the pain comes back". No matter what you give them, the pain doesn't go away. (Professional 1)

Professionals supported the use of nonpharmacological therapies but complained about the difficulties encountered in accessing them, due to the fact that they are not included in the services provided by the public health system.

Many cases are being referred to rheumatology and rehabilitation, to specialist doctors in rehabilitation and some are sent to psychiatry, to teams of, to psychiatrists who use group therapy and things like that, right? But these are very specific cases, but not all patients are given this opportunity, it's not open to everyone because there just aren't the resources to offer these services to everyone. (Professional 3)

Patients: The pilgrimage from one speciality to another was repeated in the search for a treatment to make them feel better. Fibromyalgia patients complained that professionals lacked the knowledge necessary to enable them to prescribe effective treatment, and that not all professionals applied the same criteria to treat the disease. This left patients disconcerted when they were sent from one health professional to another without obtaining the solution they needed.

If I'm there and they send me somewhere else, from the traumatologist to another doctor and another, and they don't find anything wrong and they don't prescribe anything, until at last after suffering for ages they prescribe a treatment, and then when you go up before the Disability Board they say "who told you that?". (Patient 7)

Patients blamed professionals for not providing effective treatment and provide a first-hand account of the unpleasant secondary effects of the pharmacological treatments prescribed.

And they don't give you anything specific, it's all trial and error with the medication, now you try this, if it doesn't work they give you something else, because they don't know what to give you either. (Patient 4)

Patients reported resorting to nonpharmacological interventions in an attempt to relieve their pain. However, they also mentioned the cost of such treatments, which in many cases was beyond their means.

There are therapies like swimming, tai-chi, acupuncture or aerobics, but all these therapies cost money, don't they? They cost money. In order to go, I mean go to tai-chi therapy, the doctor there charges per session and I think it costs €60 a session. And the same happens with acupuncture. The gym costs money. (Patient 2)

Health professionals and patients: Professionals and patients emphasized the fact that pharmacological treatments very often had secondary effects and provided only limited benefits. They also criticized the lack of a specific, effective treatment for fibromyalgia. The professionals and patients interviewed suggested various proposals to improve care, and both groups proposed increasing the number of specialized staff involved in the therapeutic management: therapists, psychologists, rheumatologists, alternative medicine practitioners, etc. For example, many of those interviewed mentioned the need for specific units to which fibromyalgia patients could be referred.

Global therapy is necessary, management should be multidisciplinary. (Professional 6)

There's a lot to be done, if they did just that, if they just spent money on creating these multidisciplinary clinics and got everybody to sit down together: the psychologist next to the rheumatologist, next to the traumatologist, all together and said "we are going to give this person this treatment, like this, this, and this". (Patient 12)

Evaluation of the health professional-patient relationship

Health professionals: Professionals were aware of their patients' dissatisfaction with interventions. Above all, they attributed this dissatisfaction to the frustration patients felt when they did not obtain satisfactory treatment. The health professionals themselves recognized that the medication available was not very effective and was incapable, in most cases, of controlling the generalized symptom of fibromyalgia – pain. Thus, professionals attributed conflicts with patients to the difficulties involved in diagnosing and treating fibromyalgia.

People feel let down by their doctors... The degree of satisfaction is very low... Basically because we don't solve their problem. (Professional 2)

At the same time, professionals described how the characteristics of the health system itself (limited time for the consultation, long waiting lists) may negatively affect how they were evaluated by patients.

You don't have sufficient time to dedicate to patients at the moment and on the day they need it. This is a very serious limitation, because some days they feel better, other days they feel worse but you aren't there every day, you don't have the means or the time to dedicate to them. (Professional 3)

Patients: From the interviews with patients, most evaluated the health care provided by professionals negatively. Patients perceived a lack of empathy or, as many interviewees put it, only a minimum effort to provide attention, support and understanding.

Then, when you try to explain all this simply to your doctor and he doesn't raise his eyes from his desk, or doesn't stop five minutes to listen to what you're saying or, I don't know, I think it's like a cold shower, don't you? It shatters you because if the person who should give you moral support, doesn't say anything, doesn't talk to you about this. (Patient 8)

Patients were dissatisfied with how they were treated by professionals who questioned their credibility, and demanded greater involvement and empathy from them.

Because of course, when you go to the doctor, you don't expect him to give you a solution, but you do expect at least moral support, I don't know, you expect them to give you an answer, to say something. (Patient 6)

Another of the aspects that patients most criticized was the professionals' lack of knowledge concerning the disease. The majority of patients interviewed agreed that a greater knowledge of the disease would facilitate its diagnosis and early treatment.

In medicine doctors are not very well informed about this, I think that, the doctors aren't, I'm not going to say maybe well aware, or rather that they don't know much about the subject, or don't know anything. (Patient 8)

From the professionals' point of view, greater support should be provided to fibromyalgia patients to provide them with more effective strategies to deal with the problem. In this respect, some of the professionals interviewed considered that it was necessary to actively listen to patients and provide them with all relevant information as well as the psychological support necessary for them to actively deal with their disease.

Health professionals and patients: Because of these discrepancies, the relationship between health professionals and fibromyalgia patients was sometimes described as problematic. Tense situations or clashes occurred because expectations were not met. Professionals believed that their professionalism and explanations were being challenged, whereas patients once again described their feelings of dissatisfaction with the way they were treated.

And then she came once and said to me: "you've treated me very badly, the other day you took no notice of me". And it's this feeling that they always think you don't take any notice of them, right?... (Professional 1)

And he started laughing at me. I turned round and said "are you laughing at my pain?" and he said "you don't want me to cry, do you"... And I opened the door and went out crying. (Patient 12)

At the same time, professionals agreed with patients that this negative evaluation may be due to the extreme difficulty they faced in finding a solution within the health system, due in part to the number of specialists that a patient must consult and the increasing sense of frustration they felt as they were passed from pillar to post.

They go from one to the other, they find a doctor who gives them hope and they go to him. Once again they're disappointed. (Professional 2)

Doctors treat you like a yo-yo, as one might say, "go here, this test showed nothing, go there". (Patient 6)

DISCUSSION

The present study highlights and analyzes the mutual dissatisfaction that exists among patients and health care specialists regarding the management of fibromyalgia. It also explores the underlying reasons for this dissatisfaction, which are all related to the uncertainty surrounding fibromyalgia, particularly its etiology.

Our results are consistent with those of other studies, in which reaching a diagnosis is described by patients as a challenge because they often remain undiagnosed for many years or may even be misdiagnosed (44). Professionals attribute the difficulty in reaching a diagnosis to a complete lack of objective tests, as noted by other authors such as Steinberg (26). Another valid interpretation is that some professionals are reluctant to diagnose fibromyalgia because patients may become obsessed with the disease and immediately assume the role of an invalid, a habit that is difficult to break once acquired (36).

These results demonstrate that there is a dilemma concerning the balance between the potential benefits and harmful effects of fibromyalgia medication. The therapy available is palliative, not curative, and very often treatment needs be tailored to the individual patient due to symptom variability and comorbidity with other diseases. Professionals argued that fibromyalgia patients tend not to respond to conventional painkillers. Although new specific pharmacological treatments are now available to treat pain (45), the professionals interviewed could only consider the medication available at the time the study was conducted (2008). Nevertheless, the demonstrated efficacy of new drugs, such as pregabalin (Lyrica; Pfizer, USA), the first prescription medication specifically for managing fibromyalgia, is questionable and they are also associated with significant side effects (17).

Patients attempt different treatments in the search for relief and some use nonpharmacological treatments. In general, patients believe that such therapies help them more than conventional medicine (27,46,47). Psychotherapy is another common resort for fibromyalgia patients (48). According to the scientific literature, multidisciplinary therapy appears to be the best option (30,49-51). This combines pharmacological treatment with physical exercise, psychotherapy or alternative therapies such

as acupuncture, yoga or other relaxation techniques. However, health systems in Spain do not include these types of treatments. As a result, patients have to pay for many of these therapies, which has been identified as a barrier to access and the possibility of a cure.

In the present study, health professionals gave a positive view of the interest they take in these patients. However, in general, patients describe a lack of moral support from the professionals caring for them. The confrontations described by both groups may be caused by the tension created when their expectations clash (44,52). In the present study, other reasons for conflict mentioned by professionals were the limited resources available to work with these patients (eg, insufficient time for consultations). The health professionals interviewed by Ruiz Moral et al (2) and Steinhaug and Malterud (41) also reported that they distanced themselves from the patients because they felt that they could not offer them the necessary care (eg, psychological support).

Implications for practice and policy

The results of the present qualitative study have implications for clinical practice, training and research on the subject. It is a challenge for health systems to help individuals diagnosed with a chronic disease, such as fibromyalgia, to cope (24). Health system managers may also benefit from the information provided by the present study. Managing fibromyalgia requires making significant modifications, mainly regarding the type of doctor-patient relationships, new clinical competences and certain organizational aspects of health care.

It is necessary to improve the collaboration between health professionals (general practitioners, specialists, psychologists, etc) to enable health services to offer patients coherent strategies and information. As the interviews conducted in the present study demonstrate, coordination between specialities should be improved by drawing up specific guidelines or making specific units available to facilitate intercommunication between all professionals involved in the treatment and follow-up of these patients (2,19,35,49,53,54).

Patients consider a greater number of national health fibromyalgia units to be a possible means of improving management of the disease. In some regions of Spain, there are fibromyalgia clinics affiliated with hospitals or rheumatology institutes; these facilitate interdisciplinary management and collaboration of various specialities in the therapeutic treatment, thus helping to provide integral care for patients (10). In other regions, there are pain clinics to which these patients may be referred. Similar resources in other countries are referred to as interdisciplinary management programs: Pain Clinics and Fibromyalgia Clinics in the UK, and Fibromyalgia Treatment Centres or Fibromyalgia Networks in the United States, where associated diseases, such as chronic fatigue syndrome, are often treated (55).

Support from health professionals positively affects patients' quality of life (56,57). Health services (general practitioners, specialists, medical insurance companies, governmental institutions) play a key role in helping patients come to terms with the disease (58). Explanations concerning the disease are a key point in clinical communication between health professionals and fibromyalgia patients, because the latter are chronic patients with symptoms that cannot be explained medically (41,59). To improve the quality of health care and establish a closer relationship with patients, professionals should encourage a therapeutic relationship in the clinical encounter by using good communication skills (41,59,60).

Access to health professionals with expert knowledge helps to improve the management of fibromyalgia patients and their health problems (34). Patients' demands suggest that it is important for all professionals involved in managing fibromyalgia to receive specific training. This would raise their awareness of the disease and the particular needs of these patients to help them to cope and improve their quality of life. This is particularly true in the case of general practitioners because they provide access to multidisciplinary and specialized care (eg, rheumatology, psychiatry, psychology) (61).

Limitations and strengths

One limitation to the present study was that the sample of professionals was heterogeneous because they belonged to a variety of

specialities. The views most often explored in earlier studies belong, above all, to general practitioners and rheumatologists (2,37). Therefore, the experiences of the professionals participating in the present study are valuable because they provide complementary views on managing the disease from the perspective of their own particular specialities (eg, mental health specialists or occupational health doctors). In Spain, the former are involved in therapeutic management, while the latter are responsible for evaluating the level of disability to assess requests for sick leave. In future studies, other types of professionals, such as nurses or social workers, should also be included (62).

Other study samples consist exclusively of women because they are more often affected by the disease (25,31,34,63). Our sample was composed mainly of women but also included men, whose perspective as fibromyalgia patients has been studied to a lesser degree. The main strength of the present study lies in the innovative strategy of comparing the views of the two groups involved in fibromyalgia management: patients and professionals. Recent studies indicate the need to jointly examine the views of the different agents involved in fibromyalgia to provide information that is more useful than if the different perspectives are analyzed separately (33).

The present research contributes to a better understanding of why management of fibromyalgia is currently neither effective nor satisfactory. It also provides insight into how health professionals can support fibromyalgia patients to achieve beneficial results. We emphasize the need for health care services to offer fibromyalgia patients greater support through the provision of specific resources such as the fibromyalgia clinics that exist in Spain and health professionals with a greater awareness of the disease. We believe that it is necessary to examine the views of both groups together and encourage collaboration in the management of fibromyalgia.

ACKNOWLEDGEMENTS: The authors gratefully acknowledge the contributions of the patients and health professionals who participated in this research.

FUNDING: The present study was partially financed by the National Observatory of Women's Health of the Spanish Ministry for Health, Social Policy and Equality, and is part of a wider research project financed by the Regional Valencian Government's Joan Gil-Albert Cultural Institute in Alicante (Spain) and will be used as part of Erica Briones' PhD training programme and dissertation at the University of Alicante, Spain.

REFERENCES

1. Arnold LM. Strategies for managing fibromyalgia. *Am J Med* 2009;122(12 Suppl):S31-43.
2. Ruiz Moral R, Rodriguez Salvador J, Perula L, et al. [Problems and solutions in health care for chronic diseases. A qualitative study with patients and doctors]. *Aten Primaria* 2006;38:483-9.
3. Bowen J, Pheby D, Charlett A, McNulty C. Chronic fatigue syndrome: A survey of GPs' attitudes and knowledge. *Fam Pract* 2005;22:389-93.
4. Chew-Graham C, Dixon R, Shaw JW, Smyth N, Lovell K, Peters S. Practice nurses' views of their role in the management of chronic fatigue syndrome/myalgic encephalitis: A qualitative study. *BMC Nurs* 2009;8:2.
5. Epstein RM, Shields CG, Meldrum SC, et al. Physicians' responses to patients' medically unexplained symptoms. *Psychosom Med* 2006;68:269-76.
6. Lundh C, Segesten K, Bjorkelund C. To be a helpless helpoholic – GPs' experiences of women patients with non-specific muscular pain. *Scand J Prim Health Care* 2004;22:244-7.
7. Risor MB. Illness explanations among patients with medically unexplained symptoms: Different idioms for different contexts. *Health (London)* 2009;13:505-21.
8. Wileman L, May C, Chew-Graham CA. Medically unexplained symptoms and the problem of power in the primary care consultation: A qualitative study. *Fam Pract* 2002;19:178-82.
9. Branco JC, Bannwarth B, Failde I, et al. Prevalence of fibromyalgia: A survey in five European countries. *Semin Arthritis Rheum* 2010;39:448-53.
10. Carmona L, Ballina J, Gabriel R, Laffon A. The burden of musculoskeletal diseases in the general population of Spain: Results from a national survey. *Ann Rheum Dis* 2001;60:1040-5.

11. Sauer K, Kemper C, Glaeske G. Fibromyalgia syndrome: Prevalence, pharmacological and non-pharmacological interventions in outpatient health care. An analysis of statutory health insurance data. *Joint Bone Spine* 2011;78:80-9.
12. Copenhagen Declaration. Consensus document on fibromyalgia: The Copenhagen Declaration. *J Musculoskel Pain* 1993;1:295-312.
13. Wolfe F. The relation between tender points and fibromyalgia symptom variables: Evidence that fibromyalgia is not a discrete disorder in the clinic. *Ann Rheum Dis* 1997;56:268-71.
14. Wolfe F, Smythe HA, Yunus MB, et al. The American College of Rheumatology 1990 Criteria for the Classification of Fibromyalgia. Report of the Multicenter Criteria Committee. *Arthritis Rheum* 1990;33:160-72.
15. Hauser W, Thieme K, Turk DC. Guidelines on the management of fibromyalgia syndrome – A systematic review. *Eur J Pain* 2010;14:5-10.
16. Mease P. Fibromyalgia syndrome: Review of clinical presentation, pathogenesis, outcome measures, and treatment. *J Rheumatol Suppl* 2005;75:6-21.
17. Barker KK. Listening to Lyrica: Contested illnesses and pharmaceutical determinism. *Soc Sci Med* 2011;73:833-42.
18. Care Continuum Alliance. CCA definition of disease management. <http://www.carecontinuum.org/dm_definition.asp> (Accessed November 11, 2010)
19. Schiltenswolf M, Eich W, Schmale-Grete R, Hauser W. [Aims of the guidelines for diagnostic and treatment of fibromyalgia syndrome]. *Schmerz* 2008;22:241-3.
20. Clark NM, Nothwehr F, Gong M, et al. Physician-patient partnership in managing chronic illness. *Acad Med* 1995;70:957-9.
21. Von Korff M, Gruman J, Schaefer J, Curry SJ, Wagner EH. Collaborative management of chronic illness. *Ann Intern Med* 1997;127:1097-102.
22. Hellstrom O, Bullington J, Karlsson G, Lindqvist P, Mattsson B. A phenomenological study of fibromyalgia. Patient perspectives. *Scand J Prim Health Care* 1999;17:11-6.
23. Raymond MC, Brown JB. Experience of fibromyalgia. Qualitative study. *Can Fam Physician* 2000;46:1100-6.
24. Lachapelle DL, Lavoie S, Boudreau A. The meaning and process of pain acceptance. Perceptions of women living with arthritis and fibromyalgia. *Pain Res Manag* 2008;13:201-10.
25. Asbring P, Narvanen AL. Women's experiences of stigma in relation to chronic fatigue syndrome and fibromyalgia. *Qual Health Res* 2002;12:148-60.
26. Steinberg DP. The experience of relationships: Twelve people with fibromyalgia. New York: New York University; 2007.
27. Cunningham MM, Jillings C. Individuals' descriptions of living with fibromyalgia. *Clin Nurs Res* 2006;15:258-73.
28. Dobkin PL, De Civita M, Bernatsky S, Filipski M, Sita A, Baron M. Preliminary validity of the barriers to treatment adherence questionnaire in fibromyalgia: Combining quantitative and focus group data. *Psychol Rep* 2009;105:447-60.
29. Paulson M, Norberg A, Danielson E. Men living with fibromyalgia-type pain: Experiences as patients in the Swedish health care system. *J Adv Nurs* 2002;40:87-95.
30. Sim J, Adams N. Systematic review of randomized controlled trials of nonpharmacological interventions for fibromyalgia. *Clin J Pain* 2002;18:324-36.
31. Haugli L, Strand E, Finset A. How do patients with rheumatic disease experience their relationship with their doctors? A qualitative study of experiences of stress and support in the doctor-patient relationship. *Patient Educ Couns* 2004;52:169-74.
32. Escudero-Carretero MJ, García-Toyos N, Prieto-Rodríguez MA, Pérez Corral O, March-Cerdá JC, López-Doblas M. [Fibromyalgia: Patient perception on their disease and health system. Qualitative research study] *Reumatol Clin* 2010;6:16-22
33. Rodham K, Rance N, Blake D. A qualitative exploration of carers' and patients' experiences of fibromyalgia: One illness, different perspectives. *Musculoskeletal Care* 2010;8:68-77.
34. Asbring P, Narvanen AL. Patient power and control: A study of women with uncertain illness trajectories. *Qual Health Res* 2004;14:226-40.
35. Alghalyini B. That sinking feeling: A patient-doctor dialogue about rescuing patients from fibromyalgia culture. *Can Fam Physician* 2008;54:1576-7.
36. Asbring P, Narvanen AL. Ideal versus reality: Physicians perspectives on patients with chronic fatigue syndrome (CFS) and fibromyalgia. *Soc Sci Med* 2003;57:711-20.
37. Hellstrom O, Bullington J, Karlsson G, Lindqvist P, Mattsson B. Doctors' attitudes to fibromyalgia: A phenomenological study. *Scand J Soc Med* 1998;26:232-7.
38. Sim J, Madden S. Illness experience in fibromyalgia syndrome: A metasynthesis of qualitative studies. *Soc Sci Med* 2008;67:57-67.
39. Pope C, Ziebland S, Mays N. Qualitative research in health care. Analysing qualitative data. *BMJ* 2000;320:114-6.
40. Fitzpatrick R, Boulton M. Qualitative methods for assessing health care. *Qual Health Care* 1994;3:107-13.
41. Steihaug S, Malterud K. Part process analysis: A qualitative method for studying provider-patient interaction. *Scand J Public Health* 2003;31:107-12.
42. Spanish Reumatology Society. Estudio EPISER. Prevalencia e impacto de las enfermedades reumáticas en la población adulta española. Madrid: Spanish Reumatology Society 2001.
43. Miles MB, Huberman AM. Qualitative data analysis. Thousand Oaks: Sage, 1994.
44. Larun L, Malterud K. Identity and coping experiences in chronic fatigue syndrome: a synthesis of qualitative studies. *Patient Educ Couns* 2007;69:20-8.
45. Recla JM. New and emerging therapeutic agents for the treatment of fibromyalgia: An update. *J Pain Res* 2010;3:89-103.
46. Soderberg S, Lundman B, Norberg A. Struggling for dignity: The meaning of women's experiences of living with fibromyalgia. *Qual Health Res* 1999;9:575-87.
47. Pérez-Martín A, López-Lanza JR, Avellaneda-Fernández A. Evidencias en fibromialgia. *FMC* 2007;14:465-73.
48. Lempp HK, Hatch SL, Carville SF, Choy EH. Patients' experiences of living with and receiving treatment for fibromyalgia syndrome: A qualitative study. *BMC Musculoskel Disord* 2009;10:124.
49. Angst F, Verra ML, Lehmann S, Brioschi R, Aeschlimann A. Clinical effectiveness of an interdisciplinary pain management programme compared with standard inpatient rehabilitation in chronic pain: A naturalistic, prospective controlled cohort study. *J Rehabil Med* 2009;41:569-75.
50. Goldenberg DL, Burckhardt C, Crofford L. Management of fibromyalgia syndrome. *JAMA* 2004;292:2388-95.
51. Strobel ES, Wild J, Muller W. [Interdisciplinary group therapy for fibromyalgia]. *Z Rheumatol* 1998;57:89-94.
52. Salmon P, Peters S, Stanley I. Patients' perceptions of medical explanations for somatisation disorders: Qualitative analysis. *BMJ* 1999;318:372-6.
53. Bruckle W. [Fibromyalgia – the new guideline]. *Z Rheumatol* 2009;68:451-8.
54. Scascighini L, Toma V, Dober-Spielmann S, Sprott H. Multidisciplinary treatment for chronic pain: A systematic review of interventions and outcomes. *Rheumatology (Oxford)* 2008;47:670-8.
55. Stanos S, Houle TT. Multidisciplinary and interdisciplinary management of chronic pain. *Phys Med Rehabil Clin N Am* 2006;17:435-50, vii.
56. Hallberg LR, Carlsson SG. Coping with fibromyalgia. A qualitative study. *Scand J Caring Sci* 2000;14:29-36.
57. Schoofs N, Bambini D, Ronning P, Bielak E, Woehl J. Death of a lifestyle: The effects of social support and healthcare support on the quality of life of persons with fibromyalgia and/or chronic fatigue syndrome. *Orthop Nurs* 2004;23:364-74.
58. Crooks VA, Chouinard V, Wilton RD. Understanding, embracing, rejecting: Women's negotiations of disability constructions and categorizations after becoming chronically ill. *Soc Sci Med* 2008;67:1837-46.
59. Arillo A, Vilches C, Mayor M, Gurpegui JR, Arroyo C, Extremera V. [Frequent users and difficult patients: How do they feel about their treatment by doctors?]. *An Sist Sanit Navar* 2006;29:47-58.
60. Kenny DT. Constructions of chronic pain in doctor-patient relationships: Bridging the communication chasm. *Patient Educ Couns* 2004;52:297-305.
61. Arnold LM, Clauw DJ. Fibromyalgia syndrome: Practical strategies for improving diagnosis and patient outcomes. *Am J Med* 2010;123:S2.
62. Alameda Cuesta A, Pazos Garcíandia A. [Qualitative research on the conceptualization around the frequent attendance by primary medical staff]. *Rev Esp Salud Publica* 2009;83:863-75.
63. Undeland M, Malterud K. The fibromyalgia diagnosis: Hardly helpful for the patients? A qualitative focus group study. *Scand J Prim Health Care* 2007;25:250-5.