



Original article

Fibromyalgia: Patient perception on their disease and health system. Qualitative research study

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ABSTRACT

Objective: To know the experiences and expectations of persons with fibromyalgia towards the health system and its professionals.

Methods: Qualitative study with three focal groups. The first focal group included patients with fibromyalgia, 20 women and 1 man, receiving care in the public health system, with different assistance paths and progression. Informed Consent was required. Content analysis was done.

Results: Patients describe a difficult experience, with symptoms that may involve incapacity for daily activities. Until knowing their diagnosis, they feel a lack of understanding and also loneliness. They develop different coping strategies, as looking for information or association. From the health system they expect: attention and a fast diagnosis, accessibility to consultations, medical exams and therapies or an impulse for research. They want trained professionals, proactive attitudes, interest, empathy and information.

Discussion: Qualitative methods seem suitable for delving into patient experience. Health assistance must improve patients' quality of life, facilitating their assistance process and offering companionship, interest, comprehension and support.

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Fibromialgia: percepción de pacientes sobre su enfermedad y el sistema de salud. Estudio de investigación cualitativa

RESUMEN

Objetivo: Conocer la experiencia y vivencia de personas con fibromialgia y sus expectativas sobre el sistema sanitario y sus profesionales.

Métodos: Diseño cualitativo a través de grupos focales. Se realizaron tres grupos, uno con pacientes que pertenecían a asociaciones de fibromialgia. Participaron 20 mujeres y 1 varón. Se incluyeron personas que recibían atención en el sistema sanitario público, con distintas trayectorias asistenciales y evolución. Se pidió consentimiento informado. Análisis de contenido.

Resultados: Describen una vivencia difícil con una sintomatología que puede ser incapacitante para las actividades cotidianas. Hasta que reciben el diagnóstico, perciben incompreensión y soledad. Desarrollan distintas estrategias de afrontamiento, como buscar información o asociarse. Esperan del sistema sanitario: atención y diagnósticos ágiles, acceso a consultas, pruebas que necesiten y terapias beneficiosas o impulso a la investigación. Quieren profesionales con formación para abordar la fibromialgia, una actitud proactiva, interés, empatía e información.

Discusión: La metodología cualitativa fue idónea para profundizar en la experiencia de pacientes. La atención sanitaria debe dirigirse a mejorar su calidad de vida facilitando su proceso asistencial y ofreciendo acompañamiento, interés, comprensión y apoyo.

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Introduction

Fibromyalgia was recognized as a disease by WHO in 1992. This is a clinical syndrome of unknown etiology, which causes chronic, diffuse and disabling musculoskeletal pain. The disorder is often accompanied by fatigue, sleep disturbances, headaches or irritable bowel syndrome, among others.¹⁻⁵

The rate of patients with these symptoms account for up to 20% of first time patients seen at two rheumatology centers. It is estimated that fibromyalgia affects between 2 and 2.7% of the Spanish population over 20 years,⁵⁻⁷ being much higher in women: 4.2% (0.2% men)⁵ Several authors have also characterized a significantly reduced quality of life in sufferers.^{7,8} For these reasons, as well as the health resource consumption involved, it is a public health problem of the first order^{1,3,9} and has aroused a growing interest in the scientific community. This is evidenced by the increase in research and articles published on the subject, which in the period of 1996–2005 more than tripled with relation to the previous decade.⁸ Most of these articles are about pathophysiology, diagnostic criteria and classification and treatment evidence.⁸ Fewer studies were performed from a psychological perspective, and of these, most are quantitative studies published after 1989.^{8,10}

Research and knowledge generated around the fibromyalgia point to interesting discussions: whether it is a disease, how to make a diagnosis, how to reduce the recurring visits of these patients to health services, the usefulness of self-help groups and educational interventions, which consultation is ideal for monitoring or the professional expectations about it.^{2,11-15}

We know the epidemiological profile of people with fibromyalgia, we are aware of the clinical aspects of the disease and what health experts think about it, but barely know the experience of these people and their position regarding the debates. There are, however, some recently published, qualitative studies that provide the experience of people with fibromyalgia and improve and deepen our understanding of the effects of the disease. These studies primarily address the

disease through the experience of symptoms associated with it,^{10,16} the benefits of participation in self-help groups,¹⁷ the importance of labeling their condition with a diagnosis,^{10,18,19} the coping strategies used before and after reaching it,^{16,18} and the perceived stigma from the disease.¹⁹

This line of research refers to this article, which aims to deepen the description and understanding of the expertise and experience of fibromyalgia patients, researching their expectations about health care and professionals.

Methods

Qualitative design based on focus groups.

Technical focus group: semi-structured group interview in which relevant issues are raised for research.^{20,21} The information gained from the experience and knowledge of participants and enriched by their interaction.²¹⁻²³

Participants: a theoretical profile was defined on the basis that there was a segmentation of the study population.^{20,21} Were established the following inclusion criteria: diagnosed with fibromyalgia who received care in the public health system, with different paths of development assistance and times, and to participate or not in patients' associations. It also sought people of both genders and different ages. The participants were contacted through health professionals in the Andalusian Health Service and patients' associations, following the above criteria.

The Andalusian Health Service belongs to the Andalusian Public Health System. This is done in the context of a health system that is public (Beveridge), guided by the principles of universality of care and equity in access to it.

The study involved 21 people: 20 women and 1 man, aged between 33 and 62 years, eight people were involved in an association of patients with fibromyalgia (Table 1).

Group formation: three focus groups were formed, one with the associated patients themselves, who were in Granada (one) and

Table 1
Composition of the structural sample

Focal group	No. of persons and gender	Age	Years with symptoms	Years since diagnosis	Occupation	Schooling
Group 1: Granada Unassociated patients	7 women	33-62 years	Between 4 and 35	Between 0 and 7	2 housewives 3 unqualified workers: cleaning and agriculture. 1 salaried (services sector) 1 student	1 no studies 4 primary schooling 1 Professional Occupational Formation (POF) 1 university studies
Group 2: Sevilla Unassociated patients	5 women 1 male	39-58 years	Between 2 and 28	Between 2 and 6	2 housewives 1 administrative (public administration) 3 services sector	2 primary schooling 2 secondary studies 2 FOP
Grupo 3 Sevilla Associated patients	8 women	43-61 years	Between 15 and 40	Between 1 and 10	2 head of private enterprise 1 unqualified worker 1 professor 2 services sector 2 housewives	1 primary schooling 4 secondary studies 3 university studies
Total	20 women 1 man	33-62 years	Between 2 and 40	Between 0 and 10	6 housewives 4 unqualified workers 6 salaried (services sector) 1 student 1 administrative (public administration) 1 professor 2 head of private enterprise	1 no schooling 7 primary studies 6 secondary studies 3 FOP 4 university studies

Table 2
Study script

Theme	Questions
Symptoms	What were your first symptoms and how did they evolve?
Health services	What services have you employed? (primary care [PC] and specialized care [SC])
Diagnosis	Where were you diagnosed?
Follow up	Who is in charge of your follow up? Who should be in charge of your follow up? (PC and/or SC)
Degree of knowledge	What do they know about fibromyalgia? What explanation have you received from the health care system (when diagnosed with fibromyalgia)? What information do you need? What information should be provided to people with fibromyalgia?
Therapy	What therapies have you tried? What are those therapies about? Which have offered benefit and which have not? Effective therapies? Which worked? Do you take drugs?
Degree of dependence	What is your degree of autonomy for activities of daily living? Are you dependent to some degree? Do you need someone to help you?
Support	What family support do you have? What support do you need from the health care system in order to improve your quality of life?
Health care	What attention does the health care system need? What would you like attention to be at the clinics? (PC and SC)
Professionals	What would good attention from the family physician be? And specialized care?
Patient associations	How did you begin to work?, What do you do? How do you obtain your information? How does a person who contacts your association evolve?

Seville (two). The groups were led by the same person on the basis of an interview script (Table 2). The duration of each group meeting ranged from two to three hours. The information was recorded and transcribed verbatim.

Informed consent: participants were informed of the objectives and characteristics of the study and requested verbal consent to participate and to record the session. They were guaranteed confidentiality and anonymity.

Analysis: content analysis was made with support from the VIVO Nudist software package. Phases: 1) careful reading of transcripts, 2) definition of categories of analysis (code tree) from the study objectives and the information obtained, 3) assignment of codes to text fragments, and 4) interpretation, systematization and discussion of results.

Validity: guaranteed through different strategies: a methodological design consistent with the purposes of research, comparison of results with other studies and triangulation of analysis and interpretation of research results between the researchers.^{20,24}

Results

Experience of fibromyalgia

"I had an active professional life, family life...like most people...The pain has been progressive...Until I was diagnosed, I did not know that it was fibromyalgia, having been through a lot of specialists, that was an ordeal. That is, a constant struggle trying to find out what I had. When I was diagnosed with fibromyalgia, and began active and personal fight, and say, "Hey, what is this?", To study, to seek and fight to control this..."

The participating patients describe very different symptoms (Table 3). They claim that their illness lessens their quality of life and even "comes to be disabling" and hard to bear. When experiencing a crisis, any activity can become an enormous effort, even those simple

"like brushing your teeth or putting on shoes." It affects their ability to perform daily activities, chores or paid work. At this point they feel 'left out, stop having fun, feel "listless".'

*"I have no desire to make love. I cannot go to a dance, I cannot wear heels because I'm tired...It changed my mood completely. For me, the late night is fatal. When noon arrives, I do not want to see anybody."
"...and I have crutches. I had to hire a woman to help in my house because I could not move, or wash, or anything. My husband had to shower me. It affected everything, that is the back, legs...led to a very great crisis."*

The experience of pain and other symptoms also leads to "changes of mood and character," to experiencing "stress and anxiety", which makes it "more difficult day by day" and reducing their "circle of support."

"My husband withstands the greatest, I start: "Aaaaay, I want to die, do not touch me!". And my husband says: "It is true that you're going to go crazy"."

This condition is aggravated by the lack of understanding they receive from the people around them, especially when undiagnosed, and lack of understanding of their health professionals, especially when they claim that their ailments are "figment of my imagination" that they "are crazy", have "bad nerves", that they "somatize" or are "hysterical."

"They treat us like we are crazy. They sent me to a psychiatrist..."

Most of these people have visited the health system for years in search of a diagnosis. Time to diagnosis varies from months to 23 years. Ignorance about the problem and possible solutions, the uncertainty and lack of understanding contributes to anchoring them in a state of depression and negative attitude.

Table 3
Most commonly referred symptoms from fibromyalgia patients

Symptom	Discursive fragment
– Pain	"It hurts wherever you touch me. Its horrible"
– Paresthesia/dysesthesia	"...a tingling on the arm, the legs..."
– Dryness of the eyes, nose, mouth, vagina, etc.	"...I also have a dry mouth and a saliva-like spray has been prescribed to me, to form saliva..."
– Restless legs	"–As well as restless legs" "–Yes, also"
– Stinging	"... a stinging sensation I cannot take any more, stinging on the whole body..."
– Joint problems	"I have carpal tunnel syndrome in both hands (...) and the joints are becoming useless and this produces fatigue when I move"
– Difficulty sleeping and resting	"I go to bed at 2:00 and wake up at 6:00, because I can't be like that any more. And what's more, if I managed to sleep, but not even for those hours"
– Fatigue	"... as if the world was on my shoulders, as if I weighed a thousand kilos, I can't explain it"
– Anxiety/tachycardia	"First you start with tachycardia, anxiety, sweating..."
– Depression	"All of the afternoon and night crying...Not eating" "I am worthless"
– Bad humor	"I don't want to know anything about nobody"
– Concentration and memory problems	"...lack of concentration" "I have recent and old memory loss...and apart from that, amnesia, my mind is a blank"
– Loss of orientation	"I have gotten lost on the street"
– Dizziness/loss of consciousness	"Dizziness and loss of consciousness? I have" "I have, also"
– Cystitis	"A lot of cystitis too, I don't know if you have had it" "I also had it"
– Tense jaw	"I've passed 15 days with my jaw..., fixed, tense"
– Early menopause	"I had my menopause at 38"
– Diarrhea/constipation	"Now that you mention the stomach, it also gives diarrhea, diarrhea and constipation"
– Hypertension	"... occasionally my pressure goes up"
– Hearing disturbances	"Sound bothers me when there is a lot of people"
– Visual disturbances	"My eyesight is terrible"
– Claustrophobia	"When I have to get into an elevator I don't want to go in there alone"
– Low body temperature	"I have taken my temperature and it was around 34"

"I feel personally like crap, you sink because you say: "Well, if I have nothing, why am I so wrong? And how can I show it? I have not a document, I don't have an analysis that says I..." I had no quality of life, I could not live."

This vicious circle is broken when receiving the diagnosis. Being called as a person with "fibromyalgia" helps them to confront the disease, learn to live with it and find coping strategies such as alternative therapies or information.

"Then you say: "I have fibromyalgia, this is what you get", and you begin to learn, no?, incorporating it into my life, seeing my side of the story, and removing what you think hurts you."

"I was diagnosed at 81 years, I can not forget this, because it was for me a total release. The information is important; having good information is 50%."

Association with other patients is a strategy that has been used by some respondents. They show a better attitude towards the disease, are more informed, they feel safe and live better with the disease, seem to be more positive than those who do not attend an association of patients. They explain these positive benefits for support of other patients, partners and specific services offered by the association.

"At that first meeting, they give you a hug when you leave, and you say, "I'm much better than when I came in"."
"I feel understood and covered"

Expectations of the health system

All interviewees refer care processes they define as "long and painful". For years, they journey through disparate points of the health system (Table 4). While their paths are specific and personal (no two processes are the same), all agree in having visited the

Table 4
Clinics visited by fibromyalgia patients in the SSPA

Clinics visited in the SSPA	
Family medicine	Pain unit
Emergency room	Cardiology
Rheumatology	Digestive
Traumatology	ENT
Rehabilitation	Oculist
Psychiatry	Vascular
Psychology	

SSPA indicates Sistema Sanitario Público Andaluz.

Rheumatology clinic, Family Medicine, Orthopedics, Psychiatry and Emergency Room and that this pathway is done routinely in primary care (in the public health system).

The people interviewed expect the health system will help them live with fibromyalgia, improving their quality of life (Table 5).

"That it will help us to live with this disease."
"Having a little better quality of life...because we are still young."

1) Ensuring quick access to consultations and the evidence they need, in a reasonable amount of time and continuity of professionals, especially for the diagnosis. An early diagnosis would reduce the anxiety that patients feel about the lack of information. It also would help remove misconceptions. For example, many patients interviewed think that it is a degenerative disease. This idea is more common in people who do not belong to associations of patients.

"Don't let them give you an appointment in two years, eh...and then the orthopedic surgeon and rheumatologist leave you without treatment. And to facilitate the issue of appointments, diagnostic tests to see the evolution."

Table 5
Needs and expectation of patients regarding the health system

- Do everything possible to IMPROVE QUALITY OF LIFE
- Guarantee ACCESS to health services and specialty clinics
- PROMPT attention
- CONTINUITY of professionals at clinics
- Performance of necessary and sufficient DIAGNOSTIC TESTS for diagnosis
- Access to ALTERNATIVE THERAPY that will benefit them such as acupuncture
- Improved access to REHABILITATION AND PSYCHOLOGY
- A good definition of the assistance process
- Creation of FIBROMYALGIA SPECIALIZED UNITS
- Promote RESEARCH on fibromyalgia
- Resources for research
- Resources for patient associations

"That it has degenerative effects, to me it is degenerating everything (...). I have a friend that, yes, they have been gradually getting more complicated..."

"I would like the specialist who saw me to be always the same, because if you go three times, I see three different chiropractors, it does not give me any confidence."

2) Increase access to Rehabilitation and Psychology and expand the range of services to other areas that the patients report as improving their quality of life, such as gymnastics, swimming and acupuncture.

"...To improve our quality of life (...) we could have rehabilitation and it does not take two or three years to get an appointment."

"We should have good social psychologists for sure."

"And all the alternative therapies that there are: acupuncture, acupressure, spa..."

3) Defining the care process of fibromyalgia and establishing minimum standards of care for these symptoms serve to expedite care. Patients consider that in a good process of care, once the diagnosis is made, specialists would not be needed except for crisis or treatment of complications.

"The follow-up for me is important, but not as dramatic. For me, it is more dramatic when one person is eight years searching."

4) Subsidizing patients' associations to continue to perform their support duties.

"And grants to help associations."

5) Promoting research on fibromyalgia, its etiology and treatment, dedicating sufficient resources to find answers to improve quality of life.

"I would like very much to hear about research about this disease... This is not going away, its a disease that is there for us and we must learn to live with it, but, please!, improve quality of life."

Expectations about health professionals

Patients with fibromyalgia go to a doctor hoping to find professionals who show interest in their illness and who have sufficient training and information on fibromyalgia in order to make a diagnosis. They also expect their professionals to devote them enough time in the clinic (Table 6). And finally, they expect them to be honest enough to acknowledge its difficulty to treat them if they do not have enough specific training on fibromyalgia and refer them

Table 6
Needs and expectations of patients regarding health professionals

- That they show INTEREST for each one of the fibromyalgia patients, that symptoms are studied, adequate studies are solicited and referral is done on a timely manner
- That they show understanding of their problem, the experience each patient is going through and their situation
- Access to INFORMATION on fibromyalgia
- That they have the ability to inform patients on what to expect of the disease and health care process, and what to do to improve their quality of life
- Educational tools to treat fibromyalgia
- TOOLS for an EARLY DIAGNOSIS
- Tools for differential diagnosis
- More time for each patient
- To LISTEN to each patient
- To establish rapport and a THERAPEUTIC RELATIONSHIP

to other professionals. Interestingly, honesty and understanding are the three key words.

"First, enough time, because with the three minutes they have, or the five minutes you have with the doctor, we cannot be addressed properly in order to diagnose what we have."

"I would like them to study you and not only give you a pill for the sake of prescribing something..."

Patients request information on what they can expect from their disease and its process, about their prognosis, therapy and care. Consistent information between professionals is also important.

"And teach the patient, when you have the disease, explain what you have, what you're going to suffer, what is going to be good...and that life has a message of hope, because you do not know if tomorrow there is going to something else."

They also hope that the professionals understand and support them, develop communication skills, especially empathy, and give them respect.

"Interest, to show interest. Not to tell you that this is something that you have made up."

"A little understanding means more than anything else."

"Whoever takes you, what you need is good communication with me, I look into your eyes, you know who I am and what is wrong with me and how I have to try and overcome it."

Discussion

Qualitative research methods have enormous potential for investigation in health sciences, as they allow access to information that is difficult to reach through other methods and deepen the understanding of complex phenomena. They are a major instrument for the continuous improvement of health services. Qualitative research techniques give voice and character to the active subjects who participate in these studies.^{20,22-24}

This was essential in the case of people with fibromyalgia, a disease that on the one hand is little known and analyzed from the point of view of their social and emotional consequences, as well as a disease with profound implications from the psychic and somatic standpoints. This study gets us closer to the reality of people with fibromyalgia, which is essential in qualitative research, listening to their experience and assigning meaning to that first-person experience.^{20,21,25} This is the main added value of our results. The study also presents some limitations. It was only performed in groups of associated patients; if we had done it in other circumstances, we could compare the experience of other patients. We included a man in

the sample, but we believe it would have been interesting to include more and check if the experience and assessment of both genders is different or similar. Both are suggestions for future research.

In connection with the dual aim of this study, the results have been organized into two blocks: the experience of fibromyalgia and expectations about the healthcare system and its professionals.

As for the experience, the interviewees tell of a difficult and lonely experience. They feel sick and have diverse symptoms that describe a lot of events. Other published studies performed a similar description of symptoms.^{2,7,10,16,26}

Through the pain and other symptoms, the experiences of misunderstanding and uncertainty leads to anxiety, depression and isolation, which in turn could be related to the worsening symptoms. Other studies show that people with chronic painful diseases often coexist with anxiety-depressive disorders.^{3,4} Also, in the work of Junyent Priu, in a group of 130 patients diagnosed with fibromyalgia, 55% had an associated psychiatric disorder.²⁷

In this study, participants' time to diagnosis went from "a few months" to 23 years. In the study by Ubago, the average time was 9 years.²⁶ Respondents identified the diagnosis as an essential milestone on the road to recovery because it gives them authority over the ailment, allowing them to search for solutions and reassurance. Goldenberg's study shows that after two years after obtaining a diagnosis of fibromyalgia, 50% of people felt that their symptoms remitted without taking medication.²⁸ The frequency of visits to the clinic decreases after diagnosis as does further testing, reducing patient anxiety, allows them to share their concerns, complaints and expectations with others in the same situation and helps them concentrate on their recovery.^{2,4,10,11,16,19,26}

The patients diagnosed with fibromyalgia have to develop new strategies to address their situation, such as learning to live with the disease, look for alternative therapies and information. In other qualitative studies, these and other coping strategies are described, such as how to develop positive thinking, obtain distraction through leisure activities, perform daily exercise, continue with normal activities and manage everyday use of professional or spiritual help, accept new constraints, reorganize life or increase the control of the situation as well as deal with encounters with medical staff.¹⁶⁻¹⁹

In this search for alternatives and information, some women resort to patient associations. One result of this study is that people with fibromyalgia who participate in an association of patients are more informed, have a more positive attitude and live better with their problems. Partnership provides information, support, reinforcement, entertainment and, sometimes, alternative therapies, aspects that patients value significantly.^{10,12} Some studies on fibromyalgia have shown that educational interventions and self-oriented activities improve the quality of life,¹² help them know themselves better and develop certain necessary skills for coping with the disease, such as choosing to act for themselves or to negotiate.¹⁷ According to Narvanen Asbring, socializing with other patients becomes a way of being accepted and accepting.¹⁹

As for the other component of the outcome, expectations of the health system and its professionals are synthesized in the importance of achieving improved quality of life and the need for professional assistance.

Seeking therapy helps them live better with the symptoms.⁶ They demand more flexible and accessible service, with continuity of professionals, both for diagnosis and follow-up. They value the development of research on fibromyalgia, its causes and new treatments. These expectations on the healthcare system coincide with those expressed in studies of other chronic diseases.^{8,29-31}

As for the attention of the health professionals, they expect interest, understanding, empathy and communication skills, as well as knowledge about the disease and the transmission of skills and information on them. Martínez Lavin, in his study of doctor-patient relationship in fibromyalgia, pointed out that it was important,

as in other chronic diseases, that doctors accompany the patient throughout the process and exchange points of views.¹⁵ The need for information is also highlighted in this article.^{4,14} The importance of understanding and support, active listening and dedication of time are highlighted by Rotés Querol.⁷

In conclusion, health care for patients with fibromyalgia should be targeted to improving their quality of life, streamlining the diagnosis, reducing anxiety, facilitating the process of care and offering support, caring and understanding from the professionals. It must focus on the health of patients by providing comprehensive care, incorporating their expectations, providing knowledge and training to meet their self-care and allow them to become active agents of their health process as well as supporting self-help and patient groups.^{5,12,32}

Actions that seek to improve care of these patients

It is interesting to mention an initiative of the Ministry of Health of Andalusia: the creation of a School of patients with the aim of improving training and information of chronic patients. It began in 2008 with the Fibromyalgia classroom and the development of various information and educational materials (www.escueladepacientes.es).

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