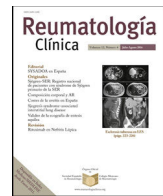




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Review article

## Patient-journey of fibromyalgia patients: A scoping review

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### ABSTRACT

**Background:** Fibromyalgia (FM) is a chronic disease characterized by widespread pain. Although much is known about this disease, research has focused on diagnosis and treatment, leaving aside factors related to patient's experience and the relationship with healthcare system.

**Objectives:** The aim was to analyze the available evidence on the experience of FM patients from the first symptoms to diagnosis, treatment, and follow-up.

**Methods:** A scoping review was carried out. Medline and the Cochrane Library were searched for original studies or reviews dealing with FM and focusing on "patient journey". Results were organized using a deductive classification of themes.

**Results:** Fifty-four articles were included in the qualitative synthesis. Five themes were identified: the patient journey, the challenge for the health systems, a complex doctor–patient relationship, the importance of the diagnosis, and the difficulty of standardizing the treatment.

**Conclusions:** This scoping review confirms the negative impact of FM on the patient, their social environment, and health systems. It is necessary to minimize the difficulties encountered throughout the diagnosis and follow-up of patients with FM.

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### Patient-journey del paciente con fibromialgia: una revisión de alcance

### RESUMEN

**Antecedentes:** La fibromialgia (FM) es una enfermedad crónica caracterizada por dolor generalizado. Aunque se sabe mucho de esta enfermedad, la investigación se ha centrado en el diagnóstico y el tratamiento, sin valorar la experiencia del paciente y la relación con el sistema.

**Objetivos:** El objetivo fue analizar la evidencia sobre la experiencia de los pacientes con FM desde el inicio de los síntomas hasta el diagnóstico, el tratamiento y el seguimiento.

**Métodos:** Se realizó una revisión de alcance. Se buscaron en Medline y en Cochrane Library estudios o revisiones sobre la FM y "patient journey". Los resultados se clasificaron mediante deductiva de temas.

**Resultados:** Se incluyeron 54 artículos en la síntesis cualitativa. Se identificaron cinco temas: el viaje del paciente, el reto para los sistemas sanitarios, la compleja relación médico-paciente, la importancia del diagnóstico, y la dificultad de estandarizar el tratamiento.

**Conclusiones:** Esta revisión confirma el impacto negativo de la FM en pacientes, su entorno social y sistemas sanitarios. Es necesario minimizar las dificultades durante el diagnóstico y seguimiento de pacientes con FM.

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#### Palabras clave:

Fibromialgia  
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## Introduction

Fibromyalgia (FM) is a chronic disease characterized by chronic pain, with a prevalence between 0.5% and 5.0%,<sup>1</sup> affecting women 2–7 times more often than men.<sup>2</sup> On top of the cardinal symptom of widespread chronic pain, people with FM complain of many other symptoms, such as sleep disturbances, fatigue, joint stiffness, cognitive problems, headaches or migraines, paraesthesia, and irritable bladder or bowel, among others.<sup>3</sup>

FM is often underdiagnosed,<sup>4</sup> even though the diagnosis of FM has been shown not only to increase patient satisfaction<sup>5</sup> but also to reduce healthcare resource utilization and attendance.<sup>6</sup> This is so because FM is often incorrectly perceived as a “diagnosis of exclusion”.<sup>7</sup>

Much is known about FM, including its possible causes, the pain mechanisms involved, the long-term prognosis, and even which treatments are effective, and which are not. However, the wide range of healthcare professionals visited by people with FM has limited or biased knowledge of the disease and management options.<sup>8–10</sup>

Research has primarily focused on diagnosis and treatment, while organizational aspects of care for people with FM have been neglected. This evidence gap was highlighted in the recommendations for the management of FM by the European Alliance of Associations for Rheumatology (EULAR) updated in 2017.<sup>11</sup> To implement changes in organizations it is critical to understand the context. More concretely, in FM it is relevant to understand which are the friction points with the health system and the gaps that lead to this situation.

Recommendations for the FM management have been developed in Canada, USA, Brazil and many European countries but not in the Spanish Latin America countries.

People with FM reported mixed experiences, although negative healthcare encounters appeared to dominate these experiences. Patient needs, such as supportive attitudes by healthcare professionals, timely diagnosis, and appropriate ongoing care were unmet. Patients' care preferences are mainly unknown.

Our group is aware of the difficulties experienced by people with FM and is specifically interested in the implementation of evidence-based recommendations in Spanish speaking Latin America. As a first step, we aimed to analyze the available evidence on the experience of people with FM from the onset of first symptoms, to diagnosis, medical visits, treatment, and follow-up, as a way to better understand the general context and to serve as the basis for a more in-depth study in Spanish speaking Latin America.

## Methods

A scoping review methodology was selected. Instead of predefined research questions, our team aimed to map key concepts, primary sources, and types of evidence available in the literature on the patient journey in FM.<sup>12</sup> The review adheres to the PRISMA Extension for Scoping Reviews<sup>13</sup> (See [Supplement Material, Table 1](#)). The protocol of this review was registered on figshare.com.

### Search strategy and selection criteria

Medline via PubMed and Cochrane Library were searched for relevant articles. A broad search strategy was designed for patient-journey in FM. Search terms were synonyms of (“Fibromyalgia”) AND (“patient journey” OR “personal impact”), and the search was adapted to suit both databases. The reference lists of all articles selected for review were manually searched for additional records. The investigation was conducted in the bibliographic databases

from inception to March 2022 and was limited to articles written in English or Spanish.

Articles were eligible if reporting on the patient journey of FM or the impact of the disease irrespective of the design (quantitative or qualitative). The articles had to focus on various aspects of a patient's entire experience with FM, starting from the onset of symptoms to diagnosis and treatment. Additionally, we searched for articles that discussed patients “interaction with the healthcare system, the doctor–patient relationship, and healthcare professionals” experiences in treating FM patients. We also paid special attention to articles addressing all these aspects in Latin America. Articles were excluded if they did not report an original contribution to the research topic or did not have a full text available (e.g., conference abstracts or protocols).

### Article screening

Using the search strategy, one reviewer (TO) independently searched the electronic databases and screened the articles. The second author (LC) blindly double-screened 5% of the articles by title and abstract and 10% of the full-text articles, obtaining a 100% agreement rate with the first reviewer.

### Data analysis and risk of bias assessment

Data were extracted using a standardized template form designed for this research. A deductive narrative review synthesis method was selected to best capture the themes and findings in the identified studies. As scoping reviews aim to provide an overview of the existing evidence regardless of methodological quality or risk of bias, no critical appraisal was performed.<sup>12,13</sup> However, missing information in articles was recorded in the data extraction template to assess overall methodological reporting quality. A meta-analysis was not considered appropriate for this review, given the absence of predefined hypotheses and the qualitative nature of the majority of target studies.

## Results

The literature search returned 1539 articles after removing duplicates. The screening of titles and abstracts yielded 103 records for full-text eligibility, of which 47 were finally included in the qualitative synthesis. The list of articles included as well as their main topics are displayed in [Table 1](#). We identified 30 qualitative studies, 8 surveys, 5 observational studies, and 4 systematic reviews. The majority of studies had been conducted in European countries or the US and Canada, and 3 had been conducted in Latin America.

Five main themes were identified: (1) negative impact on the patient journey, (2) the challenge for the health systems, (3) a complex doctor–patient relationship, (4) the importance of the diagnosis, and (5) the difficulty of standardizing the treatment. Each theme is developed below.

### *Patient-journey in fibromyalgia: a significant personal and social impact*

Although widespread chronic pain is the predominant symptom, patients with FM also experience multiple additional symptoms (an average of 7 out of a list of 14 in a survey of 800 patients and more than 1600 physicians from eight countries).<sup>14</sup> The most frequent symptoms are fatigue, sleep problems, and concentration difficulties, a finding that is consistent with other studies.<sup>15–17</sup>

In addition to multiple physical symptoms, approximately one-third of people with FM also have clinically relevant levels of anxiety or depression.<sup>2–5</sup> Moreover, some authors have seen an

**Table 1**  
List of articles included.

Study	Design	Country	Topic
Arnold LM, 2008	Qualitative	US	Impact
Asbring P, 2002	Qualitative	Sweden	Disease experience
Asbring P, 2003	Qualitative	Sweden	Physician experience
Asbring P, 2004	Qualitative	Sweden	Impact
Bennett RM, 2007	Survey	US	Disease experience
Bensing J, 1991	Qualitative	Netherlands	Doctor–patient relationship
Bowen J, 2005	Survey	UK	Physician experience
Briones-Vozmediano E, 2013	Qualitative	Spain	Disease experience
Cedraschi C, 2012	Qualitative	Switzerland	Impact
Chew-Graham C, 2009	Qualitative	UK	Physician experience
Choy E, 2010	Survey	Multinational <sup>a</sup>	Difficulties in diagnosis
Clark P, 2013	Survey	Latin America and Europe	Disease experience
Colmenares-Roa, 2016	Qualitative	Mexico	Doctor–patient relationship
De Ruddere L, 2012	Qualitative	Belgium/Canada	Patient's experience/journey
Deale A, 2001	Qualitative	UK	Disease experience
Durif-Bruckert C, 2015	Qualitative	France	Doctor–patient relationship
Epstein RM, 2006	Cross-sectional	US	Doctor–patient relationship
Escudero-Carretero MJ, 2010	Qualitative	Spain	Patient's experience/journey
Glenton C, 2003	Qualitative	Norway	Impact
Haugli L, 2004	Qualitative	Norway	Doctor–patient relationship
Hauser W, 2012	Survey	Germany	Patient's experience/journey
Hayes SM, 2010	Survey + qualitative study	Canada	Doctor–patient relationship
Hoffman DL, 2008	Systematic review	US	Impact
Hughes G, 2006	Longitudinal retrospective	UK	Difficulties in diagnosis
Juuso P, 2014	Qualitative	Sweden	Patient's experience/journey
Looper KJ, 2004	Qualitative	Canada	Impact
Lundh C, 2004	Qualitative	Sweden	Physician experience
Madden S, 2006	Qualitative	UK	Difficulties in diagnosis
Mengshoel AM, 2018	Systematic review	Norway	Difficulties in diagnosis
Nettleton S, 2006	Qualitative	UK	Impact
Reisine S, 2003	Qualitative	US	Impact
Reisine S, 2008	Longitudinal prospective	US	Impact
Risor MB, 2009	Qualitative	Denmark	Disease experience
Rodham K, 2010	Qualitative	UK	Patient's experience/journey
Ruiz Moral R, 2006	Qualitative	Spain	Doctor–patient relationship
Salmon P, 1999	Qualitative	UK	Disease experience
Sim J, 2003	Survey	UK	Physician experience
Sim J, 2008	Systematic review	UK	Disease experience
Soderberg S, 1999	Qualitative	Sweden	Disease experience
Street RL, Jr., 2007	Survey	US	Disease experience
Tosal Herrero B, 2008	Qualitative	Spain	Impact
Undeland M, 2007	Qualitative	Denmark	Patient's experience/journey
Verlinde E, 2012	Systematic review	Belgium	Doctor–patient relationship
Werner A, Malterud K 2003	Qualitative	Norway	Doctor–patient relationship
White KP, 2002	Cross-sectional	Canada and US	Impact
Wileman L, 2002	Qualitative	UK	Physician experience
Wolfe F, 1995	Cross-sectional	US	Impact

<sup>a</sup> 6 European countries, Mexico, and South Korea.

association of FM with severe psychosocial processes, such as loss of total body integrity,<sup>18</sup> stigmatization<sup>19</sup> and other social problems.<sup>20</sup>

All this results in an impaired quality of life and often marked disability,<sup>4,6</sup> to the extent that the perception of general health status is worse than that of people with other chronic pain conditions, such as rheumatoid arthritis, osteoporosis, or osteoarthritis.<sup>3,15,21</sup> A survey confirmed the negative impact of FM on motivation, concentration, mobility, personal relationship, and hobbies.<sup>14</sup> The presence of FM dramatically impacts the quality of life of individuals who suffer from it, as well as their personal, family and social development, leading to breakups, added family obligations and even economic losses due to health, care and labour costs, often leading to disability for work.<sup>22</sup>

FM impacts employment to the extent that almost half of the patients missed at least two weeks of work in the last year because of FM; nearly a quarter were unable to work, and another quarter failed to work all the time because of FM.<sup>14,15</sup> In an international survey, the economic impact was more notable in Latin America than in Europe, with almost half of the patients having more than 40 days of missed work in the last year.<sup>23</sup> It has been shown that

prolonged absence from work can affect many areas of FM patients' health.<sup>24,25</sup>

#### *A challenge for healthcare systems*

Patients with FM report difficult experiences with the healthcare system.<sup>8,20,26</sup> They commonly feel disappointed, ignored, or powerless during their relationship with healthcare professionals and the system.<sup>8,27</sup> Participation in care support can also be difficult due to barriers to access to speciality medicine consultations.<sup>28,29</sup>

The non-specific symptomatology of FM and the absence of radiological, analytical and anatomopathological findings make it difficult to manage the disease from the classical biomedical approach.<sup>30</sup>

Current treatment approaches, such as physical exercise or acceptance-based cognitive-behavioural therapy, show modest, though synergistic, effect sizes.<sup>11</sup> The problem is that access to this type of care is uneven and depends on what is available or funded within each country's healthcare system.<sup>18</sup>

The European and Latin American healthcare environments are different. A survey conducted in these two regions found that, in

Europe, people with FM are primarily cared for in public healthcare versus one-third in Latin American countries, where FM patients have mainly managed in private healthcare.<sup>23</sup> This difference can make the patient's journey very different.

With these difficulties in acceptance and understanding of FM, there seems a need to include focused education for physicians regarding FM, starting ideally at medical school, to ensure all types of physicians have a basic understanding of the condition. This is particularly important for non-specialists. This is important to give the different approaches to management required for the pain of various origins, in addition to effective management of comorbidities and the multi-factorial symptoms of FM.<sup>23</sup>

Due to this lack of knowledge, Primary Care Providers have self-reported uncertainty when diagnosing and managing chronic syndromes, including FM and its diverse manifestations.<sup>8</sup> FM can also be co-morbid with various clinical conditions, including rheumatoid arthritis, depressive disorders, irritable bowel syndrome and tension-type headache, which span the scope of numerous medical specialties.<sup>31</sup> Chronic pain syndromes have often been underdiagnosed, leading to excessive testing, inappropriate treatment, and increased and prolonged healthcare utilization.<sup>32</sup>

For decades, FM has provoked debate among healthcare providers regarding its diagnostic label's clinical usefulness and diagnostic criteria.<sup>33</sup> This has been associated with barriers to accessing care; it has been found that 50% of Canadian rheumatologists, for example, have endorsed refusing referrals for consultation from patients with a reported diagnosis of FM.<sup>33</sup>

In the survey cited previously<sup>23</sup> explained that patients in Europe most commonly presented to Primary care providers (95–98%), rheumatologists (62–72%), neurologists (51–61%) and psychiatrists (21–32%) about their diagnosis of FM. The lack of a clear pathway for patients to navigate within the healthcare system has often led to siloed care, multiple medications to treat different symptoms and worsened disability.<sup>23,30</sup>

#### *A complex doctor–patient relationship*

Several studies have focused on the distress of patients who do not perceive their medical care as adequate, searching for legitimacy and their resistance to psychological explanations of pain and suffering.<sup>34–36</sup> Patients' "nomadism" and stigmatization, as well as ambiguities and difficulties in physician–patient interaction, have also been extensively investigated.<sup>18,19,37–43</sup>

In this relationship, different roles of patients with FM have been described. They may sometimes use strategies to gain control of their situation during the treatment process and to influence healthcare professionals, using their status as "experienced" patients familiar with the system and their disease to gain advantages.<sup>44</sup> Non-commitment, confrontation, persuasion, demand and emotional distancing also give them a certain degree of power in the relationship.<sup>19</sup> The patient may even learn to control the effects of medication that affect the relationship with their physicians.<sup>45</sup> Qualitative studies have revealed the efforts of women with chronic pain to maintain their credibility by trying to fit into the "expectations of biomedical correctness".<sup>37</sup>

The patients interviewed in the work of Colmenares et al.,<sup>46</sup> all of whom were treated in the public health system, report being well cared for because they undergo a physical examination and receive clear explanations from the rheumatologists and consider that they are "in good hands", despite the precarious conditions of the hospital, the long waiting times and the teaching activity, which does not allow for intimacy or patient-centeredness, and, on the contrary supports a physician-centred approach.<sup>46</sup> Åsbring and Närvänen<sup>44</sup> also describe how private medicine patients attempt to acquire

knowledge to take control of their situation with the physician, and rheumatologists recognize that these patients demonstrate ability, confrontation, insistence, and noncompliance with instructions.

From the clinician's perspective, there is an evident concern about the difficulties in treating these patients. Hayes et al.<sup>8</sup> report the feeling of helplessness experienced by physicians confronted with FM. This context of dissatisfaction and questioning of mutual trust can, as Durif-Bruckert et al. show, amplify pain.<sup>45</sup> The search for treatment is concurrent with the search for a relationship based on mutual trust and goodwill. Another paper also noted that physician prescription might signal "the physician's interest and right to access therapeutics".<sup>47</sup> The rheumatologists interviewed by Colmenares et al. alluded to several reasons for considering people with FM as "difficult patients". These reasons were longer consultation times, the demand to be listened to and to hear detailed explanations, failure to improve, emotional difficulties they do not know how to deal with, and noncompliance with treatment and instructions.<sup>46</sup> However, the interviewees expressed interest and commitment to these patients, unlike other colleagues. These findings coincide with the study by Briones-Vozmediano et al.<sup>30</sup> in which physicians found the visits of patients with FM problematic as they perceived their professionalism and explanations to be questioned, despite which they were markedly interested in these patients, empathizing and communicating with them, which is considered a benefit. Unfortunately, this perception was not shared by the patients, who, on the contrary, perceived a lack of support and attention.

In a Swedish study, the authors conclude that the strategies employed by healthcare professionals to manage patients with FM and chronic fatigue are only partially patient-centred.<sup>38</sup> Directly patient-centred approaches seek to make patients take responsibility for their condition by encouraging them to accept their situation and commit to doing something tangible for themselves. Although physicians try to make patients take responsibility for their treatment (patient-centred) and lifestyle changes, this responsibility is suggested in an authoritarian non-negotiated and routine way, as the exact instructions are given to each individual, without taking into account their possibilities of achieving them.<sup>46</sup>

Some studies have shown that, in chronic pain such as FM, the doctor–patient relationship is characterized by conflict and delegitimization between healthcare professionals and patients,<sup>37,48</sup> which means that it is not only the patient but also the relationship between the two that marks the difficulty. When the patient does not meet the "expectations of correctness" in the physician's opinion, and when, in turn, the physician does not meet them either, the relationship becomes difficult.<sup>46</sup> In the study by Haugli et al., patients interviewed expressed discomfort within a doctor–patient relationship caused by an objection to instructions on how to exercise or other recommended guidelines.<sup>48</sup> In this same study, minimization of symptoms was evident, considering some of the comments made by rheumatologists. This underestimation of the disease prevents these patients from being recognized as highly complex sick people with unique needs.

The physician's loss of control over the situation and the change of established roles also lead to rejection and stigmatization of the FM patient. The social conflict between medical ideological characteristics and the patient's disadvantaged position is one of the determining factors of the current medical consultation model, which is a real obstacle in terms of communication and social interaction.<sup>49</sup> Moreover, as Hayes et al.<sup>8</sup> shows, physicians feel frustrated with patients' demands, partly due to a lack of capacity and therapeutic tools, especially regarding psychological mechanisms and pain management.

### The anxious diagnosis

Hayes et al.<sup>8</sup> showed that primary care physicians have insufficient knowledge and skills to diagnose FM and that not all believe it to be a possible diagnosis. It has been shown, however, that labelling a disease in medical terms produces relief and reassurance for patients with FM, thanks to the legitimization of the problem.<sup>50,51</sup>

Diagnosis can have variable effects when patients are informed that the cause of their disease is unknown and the disease is not curable, causing confusion and anxiety, which is why many physicians prefer not to make this diagnosis and some refer to FM as an “empty” diagnosis.<sup>41</sup> This event, in which the diagnosis is revealed, can be associated with the pilgrimage in which the patient lives and relives his or her condition and suffering, listening to various explanations and medical expectations about its (no) cure; that is, health care may not end with the diagnosis, but recreates, again and again, the experience of the disease.<sup>46</sup> Comparing public care with private care, the pilgrimage of general care patients is more extended, and their diagnosis, after the onset of symptoms, occurs much later.<sup>46</sup>

The survey by Choy et al. focuses on the patient’s journey to diagnosis.<sup>14</sup> At the time of the survey, patients had been experiencing FM symptoms for an average of 6.5 years, with an average of 11 months before seeing a physician. Interpretation of data on time between first symptoms and attendance at the physician should be made with caution, as patients may have a history of brief, transient episodes of pain and other symptoms before persistent symptoms develop. Some patients seem to ascribe the onset of symptoms to an exact time, for example, after a traumatic event, while others may go through long periods of localized pain or other symptoms. The survey by Clark et al. studied differences in the follow-up and experience of patients with FM between Latin America and Europe.<sup>23</sup> Latin American patients reported having FM symptoms for significantly longer periods, taking much longer to be diagnosed, and seeing more physicians to receive a diagnosis than European patients. Studies in the US indicate that patients often spend 5 years before receiving a correct diagnosis of FM,<sup>7,14</sup> suggesting that, despite differences in the journey to diagnosis, patients in both regions receive a relatively similar diagnosis (Latin America: 3.5 years; Europe: 2.5 years). The time difference between the parts represents FM patients’ workload when the diagnosis is unclear. For example, pain and other symptoms (such as fatigue, sleep problems, depression, etc.) may be treated by physicians separately or even ignored.<sup>52</sup> These and similar issues are inherent variables of patients before receiving a confirmed diagnosis of FM.<sup>7</sup>

From the time patients first recall seeing a physician for their FM symptoms, it takes an average of two years, and they visit or are referred to multiple specialists and undergo numerous investigations before a diagnosis is established.<sup>6,14</sup> This diagnostic delay contributes to patient frustration.<sup>5</sup> One of the reasons of the delay is the postponement in getting the first appointment with a physician. In the survey by Choy et al., the most frequent reason (74%) for waiting to see a doctor is the belief that symptoms would resolve.<sup>14</sup> Given that FM symptoms can fluctuate in time and severity, it is not surprising that patients wait some time before seeking help from a physician. Half of the patients also waited to see a physician because they disliked taking medications or going to the doctor. Patients seek help not only because of their present symptoms but also because of the impact these symptoms have on their quality of life.

Different studies have found that patients sometimes have to persuade and “convince” their physicians that they have a real disease, that they need to be treated and that their symptoms should be recognized.<sup>48,53</sup> They want their healthcare professionals to show more interest in their disease.<sup>54</sup>

### Lack of therapeutic standardization

Treatment is provided according to the symptoms experienced by the patient and is not standardized. Differences between regions provide key insights into differential health practices. From a pharmacological point of view, FM is managed with multiple medications, although less so in Latin America than in Europe,<sup>23</sup> which may influence the negative impact of FM symptoms in Latin America versus Europe. In addition, it has been shown that treatment patterns may vary depending on the patient’s ethnicity.<sup>55,56</sup> These inherent variables may influence prescribing practices in Latin America versus Europe, especially considering European patients generally present with fewer symptoms.<sup>23</sup>

Up to 70% of patients surveyed in both regions in the work of Clark et al. had used over-the-counter drugs, highlighting the high level of self-medication in FM.<sup>23</sup> Although specific over-the-counter (OTC) treatments were not collected, and these would have varied between the different countries surveyed, even within a single region, more than half of the patients reported using OTC treatments in both areas, although significantly more among patients in Latin America than in Europe.

Aerobic exercise is helpful in patients with FM,<sup>57,58</sup> while less than 50% of the patients from Latin America and Europe report having it prescribed, and a study comparing the management of FM between Germany and the USA reports that “aerobic exercise” is used by 32% of US patients compared to 58% of Germans; however, the proportion of patients performing gentle exercise showed the opposite ratio (64% vs 80%).<sup>59</sup>

Other non-pharmacological treatment options, such as relaxation techniques and lifestyle changes, are used more frequently in Europe than in America.<sup>23</sup> Given the differences in the economics of some Latin American countries compared to Europe, these treatments may not be easily accessible or reimbursable, making their usefulness and efficacy challenging to demonstrate and implement in Latin America.

### Discussion

This scoping review has shed light on the negative impact of FM on individuals, societies, and health systems components, and has provide some structure on the difficult topics. The themes better studied are related to the patient–physician relationship and the lack of standardization concerning diagnostic and therapeutic approaches.

Chronic diseases are characterized by complex management and involve needs that vary from patient to patient but often require up-to-date knowledge and a coordinated multi- and interdisciplinary approach. This model is also true in FM,<sup>60</sup> where psychological and physical interventions can reduce the impact of disease.<sup>61</sup> However, the system often fails precisely in this need for integrated services for people with FM.

Knowledge about FM has dramatically increased, including potential causes, pain mechanisms, effective treatments and outcomes, illness experiences and the impact on people’s lives. FM is often incorrectly perceived as a “diagnosis of exclusion”.<sup>7</sup> This complexity presents a specific challenge to healthcare, further compounded by a lack of evidence-based guidelines to inform how best to organize and deliver multidisciplinary care for FM. It is known that the diagnosis of FM reduces the utilization of healthcare resources, including unnecessary referrals and tests.<sup>6</sup> However, the review has shown that there are several points of delay. One related to the patient, and a second one to the physician. Most patients feel that physicians should focus more on symptoms and spent more time with patients to arrive at a diagnosis.<sup>14</sup> Multiple symptoms in

a time-limiting context may be a determinant of this poor communication not leading to a diagnosis. In addition, many physicians are unaware of the diagnostic criteria and diagnose FM patients with outdated standards, which may underestimate FM symptoms other than pain and could lead to confusion.<sup>14</sup> Better medical training to improve knowledge and application of the criteria could reduce the delay in the diagnosis of FM.

A proper diagnostic approach leads to remarkable therapeutic success, and both depend mainly on a good healthcare professional–patient relationship.<sup>62,63</sup> Generally, we have seen that the relationship between the health system, the physician and the patient with FM is very complicated. Professionals attribute the difficulty in reaching a diagnosis to a complete lack of objective tests. 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.<sup>38</sup> Doubts about the validity of FM, lack of overt improvement, and uncertainty about diagnosis and treatment affect the interaction between physicians and patients, especially the attitude with which they confront each other. Patients with FM perceive a lack of psychosocial support, leading to mutual impatience, intolerance, and a complicated relationship.

The physician–patient relationship is an interpersonal process in which communication is vital to establish this relationship and ensure the quality of care.<sup>64,65</sup> Communication is a complex system of interaction in which reciprocity, social relationships, and patient perceptions take on particular relevance.<sup>66</sup> Research in patient–physician communication also encompasses the patient's communication style and its effect on the physician's beliefs and behaviour, among other aspects.<sup>65,66</sup> Widespread ignorance of their aetiology and frustration at not being able to address the problem cause physicians to develop an attitude of aversion and contempt towards patients with FM, according to Martínez-Lavín,<sup>67</sup> who suggests that lack of knowledge, disbelief, inadequate preparation and limited consultation times are the main problems that deteriorate this relationship, for which he proposes, as possible solutions, research, teaching, comprehensive treatment and new nosological paradigms.

Patients ask for therapies that help them to live better with their symptoms. They demand more agile and accessible services, with continuity of professionals, to obtain a diagnosis and receive a follow-up. They value the development of research into FM, its cause and new treatments. These expectations of the healthcare system are in line with those expressed in studies on other chronic diseases.<sup>54</sup>

For FM management, wellness preservation, occupational therapy, assessment, and work adjustment are crucial.<sup>24,68</sup> In this regard, the work of Clark et al.<sup>23</sup> particularly suggests that physicians should raise awareness and assist as much as possible in the normalization of the working life of these patients. Besides this, those living with the condition expressed the need for more holistic care, including support with self-management and continuity of care. A multidisciplinary care and life-course approach is needed to enable patients to live better with FM.<sup>11,69</sup> Optimizing more comprehensive health and work outcomes for those with FM has individual and societal benefits. However, a key question still to be addressed is how best to deliver multidisciplinary, holistic care in collaboration with third-sector/non-government organizations with different healthcare systems and the constraints which they pose. Future research should focus on comparing FM with other chronic pain conditions with a precise diagnosis and treatment to improve our understanding of the extent of generic versus condition-specific issues.<sup>70</sup>

Latin American patients reported having FM symptoms for significantly longer, taking substantially longer to be diagnosed,

and seeing more physicians to receive a diagnosis than European patients.<sup>23</sup> This is underdiagnosed or misdiagnosed in Latin America due to a lack of awareness among healthcare professionals. Limited knowledge and training in recognizing the condition's symptoms and diagnostic criteria can delay receiving a proper diagnosis and appropriate treatment. Also, access to healthcare specialists, such as rheumatologists and pain management specialists knowledgeable about FM, may be limited in some Latin American countries. This scarcity of specialized healthcare professionals can result in longer wait times for consultations, increased travel distances, and difficulties in receiving comprehensive care. Socioeconomic disparities can also impact the management of FM in Latin America. Limited financial resources may hinder access to healthcare services, medications and supportive therapies. Additionally, individuals with FM may face difficulties maintaining employment or experience decreased work productivity, leading to economic strain.<sup>23</sup>

Finally, we must acknowledge our limitations. The lack of confirmatory longitudinal studies and innovative mixed methods studies limits the current international understanding of the patient journey in FM. The absence of clear-cut questions in our search and data collection also makes our review limited. Another limitation of study review is that it did not consider the grey literature. However, we believe we have gathered enough information to base further our future study of the context of FM.

In light of the results of this review, it is paramount to improve the awareness and standardization in the approach to people with FM; educating physicians on the recognition and diagnosis of FM would benefit patients and health services by minimizing the difficulties encountered throughout the journey, specifically during diagnosis and follow-up.

#### Authors' contribution

Teresa Otón and Loreto Carmona contributed similarly and fully to the design of the study, analysis and interpretation of the data, critically revised the article and approved the version for publication. Javier Rivera participated in the analysis and interpretation of the data, critically revised the article, and approved the version for publication.

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#### Conflicts of interest

TO and LC have not received fees or personal grants from any laboratory, but their institute works by contract for laboratories among other institutions, such as Amgen, Fresenius Kabi España, Galapagos, Gilead, Pfizer, Lilly, Meda Pharma, MSD, Novartis, Roche, Sanofi Aventis, Upjohn, BMS, Novo Nordisk and Sandoz. JR declares no conflicts of interest.

#### Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at [doi:10.1016/j.reuma.2023.07.006](https://doi.org/10.1016/j.reuma.2023.07.006).

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