Narrative Review

“No one wants to look after the fibro patient”. Understanding models, and patient perspectives, of care for fibromyalgia: reviews of current evidence

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Abstract

Fibromyalgia is a common and complex long-term pain condition. Despite advancements in our understanding and treatment of fibromyalgia, patients report patchy health care provision and frustrating journeys through the health care system. To inform how best to deliver care, we undertook 2 narrative reviews examining existing evidence on (1) models of care for fibromyalgia and (2) patients’ experiences, preferences, and unmet needs regarding their health care. Seven databases were systematically searched. Quantitative data was narratively synthesised and qualitative data thematically analysed. No evidence-based model of care covering the patient journey through the entire health care system was identified. Limited evidence suggests no clear benefit for ongoing care in secondary care settings. Patients with fibromyalgia report difficult interactions with the health care system that might equally be expressed by those with other long-term conditions, such as inconsistent and poorly coordinated care. However, they also face unique problems; fibromyalgia was often not viewed as a real condition, resulting in difficult encounters with health care staff, in particular not feeling believed or listened to. Significant delays in diagnosis were commonplace. Positive care experiences such as being listened to and shared decision-making made patients feeling better informed, well supported, and more satisfied. There is little evidence to inform how best to organise health care for patients with fibromyalgia and ensure care is delivered in a coordinated and consistent way. These findings provide a strong rationale for developing a new model of care for fibromyalgia.

Keywords: Fibromyalgia, Narrative review, Model of care, Patient care experiences, Patient care preferences

1. Introduction

Fibromyalgia is a common long-term condition characterised by widespread body pain and symptoms such as profound fatigue and sleep difficulties.\(^{27,76}\) The estimated global prevalence among adults is 2.7%.\(^{54}\) Fibromyalgia is associated with a significant burden at an individual, organisational, and societal level.\(^{4,19,37,45,56,58,60}\) Diagnosis and management of fibromyalgia can be challenging due to its complexity.\(^{34}\) Symptoms are heterogeneous and vary in severity.\(^{8,36}\) Fibromyalgia can also occur alongside other musculoskeletal conditions such as inflammatory arthritis.\(^{27}\) However, widely used measures of disease activity and fibromyalgia.\(^{14,46}\) Knowledge about fibromyalgia including potential causes, pain mechanisms, effective treatments and outcomes, illness experiences, and the impact on people’s lives has greatly increased over time.

Yet, individuals with fibromyalgia present to a wide range of health care professionals who may have limited knowledge of the condition or treatment options.\(^{36,37,52}\) Fibromyalgia is often incorrectly perceived as a diagnosis of exclusion.\(^{73}\) Current approaches to management such as physical exercise and cognitive behavioural therapy show modest effect sizes.\(^{43}\) Access to care is patchy and depends upon what is available or funded within individual health care systems.\(^{61}\)

Patients with fibromyalgia report difficult experiences with the health care system.\(^{36,49,59}\) Feeling disappointed, ignored, or powerless in relation to health care professionals and the system can be difficult due to travel distance.\(^{71,73}\) Research to date has largely focused on diagnosis and treatments; however, there has been less emphasis on how best to organise and deliver care for individuals with fibromyalgia. This key evidence gap was highlighted in the 2017 updated European League Against Rheumatism (EULAR) recommendations on the management of fibromyalgia, which prioritised future research into care delivery.\(^{53}\)

The aim of this study was to review existing evidence on care delivery models for fibromyalgia and patient perspectives of care, to help inform the development of care provision across the entire health care system. A whole-system approach allows us to understand the patient health care journey and experience in its entirety, interactions between different parts of the system and its complexity.\(^{25,75}\)

2. Methods

We undertook 2 separate literature reviews to examine and synthesise evidence on (1) what current models of care are being...
used and (2) what are the experiences of care, the preferences for care, and identified unmet needs of patients with fibromyalgia.

2.1. Search strategy
In the absence of a standard definition,54 we defined a model of care as an evidence-informed framework that guides how best to organise patients’ journeys through the entire health care system (informed by Briggs15); and specifically how to provide “the right care, at the right time, by the right team and in the right place”.24 Although clinical guidelines or pathways (algorithms) for the management of fibromyalgia are important parts of a model of care, we understand models of care to be much broader. Therefore, the review did not include studies evaluating specific treatments for fibromyalgia.

For the purpose of this review, we defined ongoing care as any support provided after initial diagnosis and assessment such as the clinical management approach, and onward referral and access to health care services. We clustered health care services into 3 main care settings: primary, secondary/specialist (eg, rheumatology or psychiatry), and complementary care (eg, chiropractors). For the second search, we focused on studies exploring patient experiences and perspectives on care settings, processes of care, and the responsiveness of health care providers.

Each search was performed in Ovid MEDLINE(R) (1946), EMBASE (1974), AMED (1985), CINAHL, PsycINFO, Web of Science, and Cochrane CENTRAL databases. The main search concepts “fibromyalgia” and “health care provision” were combined with search-specific concepts (“model of care” and “patient experiences of care, preferences of care and unmet needs” respectively) by using Medical Subject Headings, keywords, and alternative terms. We developed initial search strategies for Ovid MEDLINER and subsequently adapted them for specific databases.

2.2. Eligibility criteria and study selection
Publications were included if they met the following eligibility criteria: (1) original, peer-reviewed, primary research study; (2) published in English or German between January 1990 and January 2018; (3) clearly defined fibromyalgia population (which was separately identifiable if several health conditions were studied); and (4) either focusing on a model of care covering the whole health care system (or specific stages of the health care journey) or patients’ perspectives of their care journey through the health care system. Studies evaluating individual treatment modalities and patient experiences of specific treatments were excluded.

2.3. Study selection, data extraction, and quality assessment
After removing duplicates, one reviewer (S.D.) screened articles by title and then abstract. Retrieved full-text publications were assessed against established eligibility criteria. Bibliographies of all included publications were manually searched to obtain additional relevant publications. Uncertainties were resolved by discussion among all the authors and reaching consensus. One reviewer (S.D.) extracted relevant data from eligible studies.

Quality appraisal was conducted by one reviewer (S.D.), using assessment tools according to the study designs. Given the relatively low number of articles, their heterogeneity and the fact that no meta-analysis was undertaken, we considered the totality of articles and their usefulness to our research questions. Hence, we did not exclude any articles based on quality assessment.

2.4. Data analysis and synthesis
Due to heterogeneity of study design of quantitative studies and outcomes measured, a meta-analysis was not conducted. Data were extracted and summarised narratively by grouping similar aspects relevant to answer the research question. Qualitative data were thematically analysed informed by the method of Braun and Clarke.12 Using an inductive approach, patterns across the data set were identified: (1) relevant aspects of text segments were coded; (2) codes were organised according to similarity of meaning; (3) themes and subthemes were developed and rechecked; and (4) finalised themes were named conveying the major idea of each theme.12 The discussion sections of the publications were consulted if necessary, to ensure correct understanding of any coded text segments.

3. Results
The findings are presented in 3 sections: models of care, patient experiences of care, and unmet needs and care preferences.

3.1. Models of care
A total of 6 studies were identified to meet eligibility criteria (Fig. 1). Eligible studies included a total of 9105 patients with fibromyalgia from 5 countries (2 from the United States, and one each from Canada, Spain, the Netherlands, and the United Kingdom). Patients attended various health care settings at different stages of their health care journeys.

An overview of selected studies is provided in Table 1. Boyer’s cross-sectional study recruited existing patients from primary care and rheumatology services in Spain to compare patient-reported outcomes (PROMs) and health care usage between these 2 care settings.11 The study focused on ongoing care, examining participants’ services use in the previous 12 months. Kroese’s randomised controlled trial in the Netherlands focused on initial diagnosis, assessing whether specialist rheumatology nurses can diagnose fibromyalgia as accurately as rheumatologists.39 Diagnostic accuracy was measured at the initial stage and at 12 to 24-month follow-up. McNett’s cross-sectional study investigated health care utilisation for patients with a diagnosis of fibromyalgia (ongoing care).47 They compared PROMs and health care usage over a 3-month period across primary care and 3 community-based clinical specialties (rheumatology, neurology and psychiatry) in the United States. Mohanty’s cross-sectional study focused on PROMs and health care usage by US Veterans in their first year after diagnosis with fibromyalgia in primary, secondary/specialist, and complementary care settings.50 Ryan’s retrospective service evaluation compared health care usage before and after introduction of a nurse-led chronic pain management clinic for patients with fibromyalgia in the United Kingdom.57 Zih et al.’s retrospective audit examined the value of any specialist rheumatology contact for newly referred patients with musculoskeletal pain or suspected/previous diagnosis of fibromyalgia in Canada, with a mean follow-up period of 16 months.

We did not identify any evidence-based model of care covering the fibromyalgia patient journey through the entire health care system (from first diagnosis to ongoing care). Studies either focused on single health care services offered at a specific stage of the health care journey or compared outcomes between different care settings.

All care settings were involved in undertaking diagnostic activities. About a quarter of patients were diagnosed with
fibromyalgia in primary care in Mohanty’s study.50 Within secondary/specialist care, most of the patients’ diagnoses were established within rheumatologist services (with 2 studies based in rheumatology).39,50,78 Mohanty showed that complementary therapists such as chiropractors also diagnosed patients with fibromyalgia.50 Little information was provided about the specific reasons for referral to secondary care; available data suggested it was to establish a diagnosis39 or to confirm a previous or uncertain diagnosis of fibromyalgia.78

Ongoing care was offered across all care settings. Two studies reported no clear benefit of rheumatology service involvement in the ongoing care for patients with fibromyalgia.11,78 Zh et al.78 reported that 116 out of 160 patients with fibromyalgia attended the rheumatology clinic more than once, with 46% of the follow-up attendees showing deterioration or no improvement regarding their health status. Another study showed a similar frequency of health care visits and PROM outcomes for patients followed up in primary care compared to specialist rheumatology services.11 Both studies concluded that primary care is an appropriate setting to provide ongoing care and may even lead to better patient care and outcomes.11,78 A third study found no significant differences in satisfaction or total care costs in patients followed up in primary care compared to secondary/specialist care (rheumatology, neurology, and psychiatry), despite important differences in clinical management of fibromyalgia.47

A wide range of health care professionals delivered care for fibromyalgia.11,39,47,50,57,78 Only one study explicitly examined the health care professions making the diagnosis.39 Kroese reported a high initial agreement between nurses and rheumatologists within the intervention group of the RCT (Kappa = 0.91;
95% uncertainty interval [0.78, 1.00] where the interval represents the 2.5 and 97.5 centiles). Nurses were trained to diagnose fibromyalgia and discussed their findings with a rheumatologist as part of the patient consultation process. The replacement of rheumatologists with specialist rheumatology nurses for diagnosing fibromyalgia was reported to be feasible and successful. After diagnosis, various health care professions were identified to support patients with fibromyalgia; nurse consultant, physiotherapist and occupational therapist, primary care physician, and specialists (rheumatologist, neuologist, and psychiatrist). Although studies stated the involvement of several health care professionals, none specifically investigated how these individuals communicated and coordinated care between different professions and care settings.

Five studies examined clinical approaches to the ongoing management of fibromyalgia. These were mainly pharmacological, provided both in primary and secondary/specialist care. Primary care or specialist nurse-led care seemed more likely to include nonpharmacological approaches such as exercise, relaxation, sleep, or stress management. Boyer reported that primary care patients scored higher using self-management coping strategies than patients attending rheumatology services. The nurse consultant-led pain management clinic study included support for ongoing self-management through an individual needs assessment and goal planning.

In relation to health care usage, Ryan et al. reported that after diagnosis, difficulties continued. A focus on health care providers; health care professionals, and time-consuming health care appointments. In comparison, Zih et al. reported that only 30% of their rheumatology patients had used nonpharmacological strategies (eg, cognitive behavioural therapy or exercise), either on advice by staff or as proactive choice self-reported by patients.

Methods studies. Studies recruited participants within and outside of health care settings, with the majority recruited from secondary/specialist care, or peer support groups (such as patient organisations or online groups). Other approaches included public advertisements. All studies (when reporting gender) comprised predominantly female participants, with the exception of one study that specifically focused on male patients. Where ethnicity, age, and symptom duration were reported, mostly white populations aged from 18 to older than 75 years were recruited, with symptom duration ranging from less than one year to 54 years. An overview of selected studies is provided in Table 2.

Patients with fibromyalgia valued and responded well to positive reactions of trust and belief shown by their health care professionals during the diagnostic process and ongoing care.

Fibromyalgia is not an illness where you can walk into a doctor’s office and… he will have a ready-made prescription for you… it needs to be very much a team experience. He needs to learn as much, if not more, from you as he can share with you. Hopefully he knows a lot about the condition and has… a lot of patients that he’s treated… he doesn’t hesitate to increase the dosage if I request it, or if I say, “I don’t feel that this is working.” So the patient has to be willing to be articulate and… the doctor also cannot come across as if it’s more to do with the head, or he has all the answers, or there is a “cure-all” remedy out there.

Many patients acknowledged tensions between their expectations of health care and what is practically deliverable within resource constraints; for example, the pressures experienced by health care professionals. Hence, they tried to book only necessary appointments and/or prepare for their health care appointments.

However, a common thread across studies was negative experiences. People with fibromyalgia reported being diagnosed by an “exclusion” approach, meaning that they had to undergo many tests, referrals to a number of different health care professionals, and time-consuming health care appointments. Patients reported that this diagnostic process often took years. A diagnosis did not automatically mean that patients felt relieved. Some patients said that they wished further diagnostic testing as they found the fibromyalgia diagnosis hard to accept.

Even after diagnosis, difficulties continued. A focus on medications, especially when prescribed without proper consultation, and no clear guidance on the next steps were perceived as unprofessional. A lack of coordination, poor continuity of care, and limited support offered by health care professionals were reported. Patients with fibromyalgia found these experiences frustrating and concerning:

### Table 1

| First author       | Year | Country       | Study design          | Care setting                                      | Health care journey stage |
|--------------------|------|---------------|-----------------------|--------------------------------------------------|--------------------------|
| Boyer et al.       | 2009 | Spain         | Cross-sectional study | Primary care, secondary/specialist care          | Ongoing care             |
| Kroese et al.      | 2008 | The Netherlands | Randomised controlled trial (RCT) | Secondary/specialist care | Diagnosis                |
| McNutt et al.      | 2011 | United States | Cross-sectional study | Primary care, secondary/specialist care          | Ongoing care             |
| Mohanty et al.     | 2016 | United States | Cross-sectional study | Primary care, secondary/specialist care, complementary care | Diagnosis, ongoing care |
| Ryan et al.        | 2012 | United Kingdom | Retrospective evaluation | Secondary/specialist care, complementary care | Assessment, ongoing care |
| Zih et al.         | 2004 | Canada        | Retrospective chart review | Secondary/specialist care | Diagnosis, ongoing care |

3.2. Patient care experiences

A total of 22 studies were eligible for inclusion (Fig. 1). This included 2776 patients with fibromyalgia from 13 countries (8 European countries, 3 from the Americas, and one each from Africa and Asia). Study designs included 3 quantitative, 16 qualitative, and 3 mixed-
| First author, year | Country | Study design | Study population | Study source | Study summary |
|--------------------|---------|--------------|------------------|--------------|---------------|
| Ashe et al., 2017  | United Kingdom | Qualitative interviews | N = 14 (female 86%)  
Age: range 29-58 y  
Symptom duration: NS | Peer support | To investigate people’s experiences of fibromyalgia and its treatments |
| Bieber et al., 2006 | Germany | Mixed-method study | N = 111 (female 91%-98%) across 3 groups  
Age: 51-52 (mean) across 3 cohorts  
Symptom duration: NS | Secondary/specialist care | To examine the impact of a shared decision-making intervention regarding encounters between patients and health care professionals |
| Boulton, 2019 | Canada, United Kingdom | Qualitative interviews | N = 31 (female 81%)  
Age: 43 y (mean)  
Symptom duration: NS | Peer support, other | To explore participants’ experiences of their diagnostic journey and their reactions to such diagnosis |
| Briones-Vozmediano et al., 2013 | Spain | Qualitative interviews | N = 12 (female 75%)  
Age: 46 y (mean)  
Symptom duration: NS | Peer support | To identify potential care provision issues from the perspective of patients and health care professionals by examining 3 aspects of managing fibromyalgia |
| Choy et al., 2010 | France, Italy, Germany, Spain, The Netherlands, United Kingdom, Mexico, South Korea | Cross-sectional study | N = 800 (female 84%)  
Age: NS  
Symptom duration: 6.5 y (mean) | Primary care, secondary/specialist care | To assess the diagnostic journey of patients and the impact of fibromyalgia on their life |
| Colmenares-Roa et al., 2016 | Mexico | Qualitative interviews, fieldwork observations | N = 8 (female 63%)  
Age: range 34-74 y  
Symptom duration: range 1-10 y | Secondary/specialist care | To explore the encounters between fibromyalgia patients and rheumatologists based in Mexican public hospitals and private clinics |
| Cooper et al., 2017 | South Africa | Qualitative interviews | N = 15 (female 100%)  
Age: range 23-59 y  
Symptom duration: NS | Peer support | To understand the difficulties of obtaining a fibromyalgia diagnosis in South Africa |
| Crooks, 2015 | Canada | Qualitative interviews | N = 55 (female 100%)  
Age: 58 y (mean)  
Symptom duration: 14 y (mean) | Peer support, other | To explore fibromyalgia patients’ strategies of interacting with the health care system |
| Cunningham et al., 2006 | Canada | Qualitative interviews | N = 8 (female 88%)  
Age: range early 30 to late 70 y  
Symptom duration: range 18 mo to 13 y | Other | To investigate participants’ experiences of living with fibromyalgia and to increase understanding about this condition and its treatment |
| Dennis et al., 2013 | United Kingdom | Qualitative interviews | N = 20 (female 95%)  
Age: NS  
Symptom duration: range 2-25 y (where specified) | Peer support | To explore participants’ broader understanding and experiences of fibromyalgia including diagnostic concerns |
| Durif-Bruckert et al., 2015 | France | Qualitative interviews | N = 35 (female 91%)  
Age: 49 y (mean)  
Symptom duration: 5 y (mean) | Secondary/specialist care | To understand fibromyalgia patients’ experiences with medications and its impact on the relationships with their doctors |

(continued on next page)
| First author, year | Country | Study design | Study population | Study source | Study summary |
|--------------------|---------|--------------|------------------|--------------|---------------|
| Egeli et al., 29 2008 | Canada, United Kingdom, United States | Qualitative survey | N = 42 (female 93%)<br>Age: 47 y (mean)<br>Symptom duration: 16 y (mean) | Peer support, other | To explore patients’ interactions (positive and negative) with health care professionals |
| Escudero-Carretero et al., 30 2010 | Spain | Qualitative focus groups | N = 21 (female 95%)<br>Age: range 33-62 y<br>Symptom duration: range 2-40 y | Health care (NS), peer support | To understand the experiences and expectations of patients with fibromyalgia regarding the health care system and health care professionals |
| Golden et al., 33 2015 | United States | Cross-sectional study | N = 1228 (85%)<br>Age: range 25-65 y<br>Symptom duration: 3 y (mean) | Other | To enhance care provision for patients with fibromyalgia |
| Lempp et al., 41 2009 | United Kingdom | Qualitative interviews | N = 14 (female 0%)<br>Age: range 41-55 y<br>Symptom duration: range 4-24 y | Secondary/specialist care | To enhance care provision for patients with fibromyalgia |
| Madden et al., 44 2016 | United Kingdom | Qualitative interviews | N = 17 (female 94%)<br>Age: range 25-55 y<br>Symptom duration: range 5-55 y | Secondary/specialist care | To explore fibromyalgia patients’ experiences of the diagnostic process |
| Paulson et al., 51 2002 | Sweden | Qualitative interviews | N = 14 (female 0%)<br>Age: range 41-55 y<br>Symptom duration: range 4-24 y | Secondary/specialist care | To explore health care experiences of male patients with fibromyalgia in Sweden |
| Sparks et al., 62 2016 | United States | Mixed-method study | N = 35 (female 91%)<br>Age: range 21-76 y<br>Symptom duration: 5 y (mean) | Secondary/specialist care | To assess the feasibility of integrating a self-management tool into clinical practice by incorporating patient views |
| Thorne et al., 67 2004 | Canada | Qualitative interviews | N = 11 (female 91%)<br>Age: range 21-76 y<br>Symptom duration: minimum 5 y | Peer support, other | To explore helpful and unhelpful communication patterns with health care professionals from the perspectives of people living with fibromyalgia |
| Ulrich et al., 68 2014 | Germany | Cross-sectional study | N = 256 (female 91%)<br>Age: range 53 y (mean)<br>Symptom duration: range less than 1 y to more than 10 y | Secondary/specialist care | To investigate the communication preferences of patients with fibromyalgia in comparison to other chronic diseases |
| Undeland et al., 69 2007 | Norway | Qualitative focus groups | N = 11 (female 100%)<br>Age: range 42-67 y<br>Symptom duration: range 3-40 y | Peer support | To investigate participants’ positive and negative experiences regarding their fibromyalgia diagnostic journeys |
| Vanderboom et al., 70 2014 | United States | Mixed-method study | N = 20 (female 100%)<br>Age: NS<br>Symptom duration: NS | Secondary/specialist care | To decide whether a technology-enhanced tool can be used for symptom tracking by fibromyalgia patients as part of their self-management |

NS, not specified; other, for example, includes approaches such as listings in newspaper/online/faculty newsletter/public notice boards, informal networks, or referrals from other participants.
So many different physiotherapists have been involved, at least 10 to 15, all trying their own various methods—this is very tiring and doesn’t lead to any overall improvement.

These experiences reportedly made it difficult to build relationships with or gain confidence in health care professionals, led to exhaustion, and hindered improvement of patients’ quality of life. In comparison, nurse-led support for self-management was seen as valuable by some patients with fibromyalgia. However, Lempp identified an absence of regular nursing input for patients.

Patients often felt that health care professionals focused on their disease instead of seeing them as a whole person. They reported limited knowledge by health care professionals regarding fibromyalgia. Patients believed that both lack of knowledge and appointment times impacted on the ability of health care professionals to diagnose fibromyalgia, ensure early treatment, and engage appropriately during consultations. Patients also reported insufficient sharing of information and/or explanations relating to the condition. How information was communicated was perceived to be as crucial as the provision of such information. These experiences reportedly led to confusion, anxiety, hopelessness, nonadherence to treatment, and seeking alternative therapies or information outside of the health care system.

Patients in both publicly funded and private-insured based health care systems experienced issues accessing care. In several studies, patients with fibromyalgia reported high personal costs related to medical care, such as attending clinic visits and private treatments. Costs seemed to accumulate especially if long-term access was needed:

“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.”

(3) Increase their knowledge about fibromyalgia-related issues
(4) Direct patients to suitable support if appropriate
(5) Invest time in building rapport, talking with and supporting those with fibromyalgia

Those living with fibromyalgia also highlighted problems at an organisational level, including the need for a timely diagnosis, more purposeful guidance through the health care system, coordinated care, as well as continuity of care by a single health care professional and across health care services. Many patients desired ongoing commitment and support by health care professionals other than medication prescriptions. Examples included providing “moral support,” problem-solving, and support for self-care as well as employment and relationship concerns. However, we did not identify any study that specifically explored patient preferences for care.

Patients thought that a range of services for fibromyalgia should be accessible within the health care system, including psychological support and rehabilitation. They specifically asked for multidisciplinary fibromyalgia specialist clinics. Health information technology was seen by patients as another useful way to increase accessibility to care for fibromyalgia. However, although there was some interest in the integration of such tools into standard care, the majority of patients still preferred to receive certain kind of support face-to-face from health care professionals.

3.3 Unmet needs and care preferences

We considered evidence about models of care for fibromyalgia and patient care perspectives in the context of the overall patient health care journey and gaps in care. Resources made available across health care systems, and specific care settings within these, shaped interactions between health care professionals and patients, as well as access to care. At the same time, health care professionals influenced these systems by their beliefs and behaviours, as well as acting as “gatekeepers” to services.

Care gaps were evident at a number of levels. At an individual level, patients reported disbelief or lack of interest on the part of health care professionals, inadequate sharing of information, and insufficient consultation times. Patients preferred open and patient-centred communication styles by health care professionals that allowed reciprocal information sharing, increased mutual understanding, and encouraged shared decision-making about care. Feeling accepted as a person by the health care professional was rated as important, potentially even more important than time and medical knowledge of the health care professional. Patients offered clear ideas on how health care professionals could improve their care:

(1) Allow patients’ experiences, expertise, and needs to be heard, then involve them accordingly
(2) Acknowledge fibromyalgia as a condition which requires people to receive health care support
(3) Increase their knowledge about fibromyalgia-related issues while being honest about gaps in knowledge
(4) Direct patients to suitable support if appropriate
(5) Invest time in building rapport, talking with and supporting those with fibromyalgia

4. Discussion

We did not find any model of care which both covered all the different aspects of health care along the entire patient journey and was evidence-based. Limited evidence suggests no clear benefit for ongoing care in secondary care settings. People with fibromyalgia reported mixed experiences, although negative health care encounters seemed to dominate these experiences. Patients needs such as supportive attitudes by health care professionals, timely diagnosis, and appropriate ongoing care were not met. Patients’ care preferences are largely unknown.

The key strength of our study is the focus on the entire health care system. Including all study designs produced a more comprehensive, refined picture of current health care delivery for fibromyalgia. Interestingly, no single research article that specified the use of patient-reported experience measures was identified. However, the review process posed a challenge with no standard definition of a model of care available. Definitions varied considerably, and numerous terms were used interchangeably. Choosing a definition deemed most appropriate for our specific purpose may have led to missing some articles, but our whole system approach enabled us to realistically reflect patient health care journeys and highlight key care gaps. Furthermore, we identified only a limited number of primary research articles (with varied study quality), which explicitly focused on the specific review questions, meaning that only data that were deemed useful for answering the review questions were included. We also
observed an overlap in articles regarding treatments and patient experiences of specific treatments. We consciously set out not to investigate this topic as part of this review nor to include the perspectives of health care professionals. Similarly, we did not include a chronic (pain) patient group with a clear diagnosis and treatment for comparison, although this may be explored in future research.

Patients with fibromyalgia report many difficult interactions with the health care system that might equally be expressed by those with other long-term conditions. For example, inconsistent and poorly coordinated care, and lack of timely access to services. However, there are unique problems faced by patients with fibromyalgia. For some health care professionals, fibromyalgia is a contested illness, and how patients are viewed by health care systems can influence care provision. A substantial number of health care professionals acknowledge their struggles to provide best care for patients because of their limited knowledge about, as well as feeling not confident or equipped dealing with, the psychosocial impacts of fibromyalgia. Many of the symptoms of fibromyalgia are similar to those in other conditions, and there are no specific blood test or scans to confirm the diagnosis, which can present diagnostic difficulties. Fibromyalgia is therefore often incorrectly perceived as a “diagnosis of exclusion.” This complexity presents a specific challenge to health care, which is further compounded by a lack of evidence-based guidelines to inform how best to organise and deliver multidisciplinary care for fibromyalgia. Consequently, a number of issues become even more important and are outlined below.

Effective patient–health care professional relationships represent a core foundation of health care and have been demonstrated to have a positive impact on patient outcomes. Building strong relationships is a mutual process, requiring investment from patients and health care professionals alike. The review showed that positive experiences with health care providers make patients feel better informed, supported, and more satisfied at any stage of their health care journey. However, difficult encounters with health care professionals along the entire patient journey, often stemming from a perceived sense of “disbelief” of the condition and subsequent mistrust, were a common thread among studies within fibromyalgia. Fibromyalgia has a wide-ranging impact on people’s lives (such as increased risk of mortality and reduced workability). Those living with the condition expressed the need for more holistic care, including support with self-management and continuity of care. To truly enable patients to live better with fibromyalgia, a multidisciplinary care and life-course approach is needed. However, this requires coordination of care across care providers (including with community, third-sector, or government services) and follow-up (eg, after referrals or crisis situations). Community-based nurses could play a key role due to their skill set and experiences in providing support for long-term conditions. The review demonstrated the promising improvements nurses can have on patients with fibromyalgia and the wider health care system. Given the range of mental health and (psycho) social concerns experienced by those with fibromyalgia, (mental) health social workers, whose support is offered across care settings and sectors, would be another valuable addition to the multidisciplinary team. Nevertheless, our review showed a lack of evidence regarding nursing input (except 2 specialist nursing roles) and the role of social and community services.

Offering patients with fibromyalgia flexible care options allows a more person-centred approach. Patients are enabled to decide, with the support of health care professionals, what works best for them. However, the ability of individual patients to make decisions and access health care successfully will ultimately be influenced by the organisation and funding set up of individual health care systems. Primary care has potential to improve health care delivery to those living with fibromyalgia. For example, Lee acknowledges the unique strengths of primary care regarding its knowledge about the populations they serve, the provision of person-centred, comprehensive care (including chronic and comorbid conditions), early intervention, continuity of care, and established patient relationships. Primary care is also well placed to support coordination, integration of, and collaboration with multiple care providers, and strong organisational relationships. Primary care also provides the first contact for patients with the health care system in many countries and is normally more cost-effective than secondary and specialist care. There is some evidence to support the diagnosis, needs assessment, and main care for fibromyalgia within primary care, with appropriate input from secondary/specialist and other services when deemed appropriate.

Our review highlights several implications for clinical practice and policy. There is a need for more clarity regarding the definition of a model of care. Such clarity enables joint understanding across settings and professions (including research and policy). Looking at the health care system as a whole also reflects more accurately how patient journeys occur in real life and, hence, the important role of health services research in fibromyalgia. Furthermore, patient care perspectives are part of the evidence base for improving quality of care. The review findings provide insights that may help to improve service delivery for people with fibromyalgia. First, health care professionals need to build trustful, ongoing relationships with patients and work with individuals’ strengths to provide real person-centred care. This care can only be achieved by exploring proactively patients’ perspectives. Second, patients want coordination and continuity of care, with timely access to holistic care. Resources to support timely diagnosis and long-term support (especially in primary care), including coordination of care activities and support for self-management, could be anticipated to have longer-term economic benefits in terms of subsequent reductions in health care utilisation and improved health and work outcomes. Third, health care services and policy makers should consider using mixed-methods approaches to gather data about patient care perspectives including patient-reported experience measures.

Optimising wider health and work outcomes for those with fibromyalgia 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/nongovernment organisations, within different health care systems and the constraints which they pose. Although our focus on fibromyalgia has enabled us to contribute condition-specific knowledge to the wider chronic pain research field, we encourage future research into the comparison of fibromyalgia with other chronic pain conditions with a clear diagnosis and treatment to improve our understanding about the extent of generic vs condition-specific issues. We also recommend future reviews into patient experiences of specific treatments and the perspectives of health care professionals.

In conclusion, our reviews reveal there is little evidence on how best to organise and deliver care for fibromyalgia across the whole health care system. Based on a small number of studies, it is indicated that secondary care settings do not offer a clear benefit for providing ongoing care for most patients with fibromyalgia. Health care provision is inconsistent and poorly coordinated, with important patient needs not being met.
Patients with fibromyalgia currently miss out on timely, appropriate, and continuous care, and their care preferences are largely unknown. These findings provide a strong rationale for developing a new model of care for fibromyalgia with the input of patients and health care providers.

Conflict of interest statement

The authors have no conflicts of interest to declare.

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