

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 [48,76]. The estimated global prevalence among adults is 2.7% [55]. Fibromyalgia is associated with a significant burden at an individual, organisational and societal level [4,19,31,45,56,58,60]. Diagnosis and management of fibromyalgia can be challenging due to its complexity [34]. Symptoms are heterogeneous and vary in severity [8,35]. Fibromyalgia can also occur alongside other musculoskeletal conditions such as inflammatory arthritis [27]. However, widely used measures of clinical disease activity used to inform treatment decisions have been shown to poorly differentiate between symptoms relating to 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 healthcare 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' [3]. 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 healthcare systems [61].

Patients with fibromyalgia report difficult experiences with the healthcare system [36,49,59]. Feeling disappointed, ignored or powerless in relation to healthcare professionals and the system are common [36,38]. Participation in care support can also 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 [43].

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* healthcare system. A whole-system approach allows us to understand the patient healthcare journey and experience in its *entirety*, interactions between different parts of the system and its complexity [25,75].

2. Methods

We undertook two separate literature reviews to examine and synthesise evidence on a) what current models of care are being used and b) 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 which guides how best to organise patients' journeys through the *entire* healthcare system (informed by Briggs [13]); and specifically how to provide "the right care, at the right time, by the right team and in the right place" [24]. Whilst 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 healthcare services. We clustered healthcare services into three main care settings:

primary, secondary/specialist (for example, rheumatology or psychiatry) and complementary care (for example, chiropractors). For the second search, we focused on studies exploring patient experiences and perspectives on care settings, processes of care and the responsiveness of healthcare 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 'healthcare 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 (MeSH), 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 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 healthcare system (or specific stages of the healthcare journey) or patients' perspectives of their care journey through the healthcare 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 (SD) 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 amongst all the authors and reaching consensus. One reviewer (SD) extracted relevant data from eligible studies.

Quality appraisal was carried out by one reviewer (SD), using assessment tools according to the study designs. Given the relatively low number of articles, their heterogeneity and the fact that 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 was extracted and summarised narratively by grouping similar aspects relevant to answer the research question. Qualitative data was 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 sub-themes were developed and re-checked; 3) 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 three sections: models of care, patient experiences of care, and unmet needs and care preferences.

3.1. Models of care

A total of six studies were identified to meet eligibility criteria (Figure 1). Eligible studies included a total of 9,105 patients with fibromyalgia from five countries (two from the US, one each from Canada, Spain, the Netherlands, and the UK). Patients attended various healthcare settings at different stages of their healthcare 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 healthcare usage between these two care settings [10]. The study focused on ongoing care, examining participants' services use in the previous twelve 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 initial stage and 12-24 months follow up. McNett's cross-sectional study investigated healthcare utilisation for patients with a diagnosis of fibromyalgia (ongoing care) [47]. They compared PROMs and healthcare usage over a three-month period across primary care and three community-based clinical specialties (rheumatology, neurology and psychiatry) in the US. Mohanty's cross-sectional study focused on PROMS and healthcare 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 healthcare usage pre- and post-introduction of a nurse-led chronic pain management clinic for patients with fibromyalgia in the UK [57]. Zih'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 [78].

We did not identify any evidence-based model of care covering the fibromyalgia patient journey through the entire healthcare system (from first diagnosis to ongoing care). Studies either focused

on single healthcare services offered at a specific stage of the healthcare 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 patients' diagnoses were established within rheumatologist services (with two studies based in rheumatology) [39,48,78]. 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 diagnosis [39] 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 fibromyalgia patients [11,78]. Zih 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 [78]. Another study showed a similar frequency of healthcare visits and PROM outcomes for patients followed up in primary care compared to specialist rheumatology services [10]. 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 healthcare professionals delivered care for fibromyalgia [11,39,47,50,57,78]. Only one study explicitly examined the healthcare 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) [39]. 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 [39]. Following diagnosis, various healthcare professions were identified to support patients with fibromyalgia; nurse consultant, physiotherapist and occupational therapist [57], primary care physician and specialists (rheumatologist, neurologist and psychiatrist) [47]. Whilst studies stated the involvement of several healthcare 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 [11,47,50,57,78]. These were mainly pharmacological, provided both in primary and secondary/specialist care [11,47,50,78]. Primary care or specialist nurse-led care seemed more likely to include non-pharmacological approaches such as exercise, relaxation, sleep or stress management [11,57]. Boyer reported that primary care patients scored higher using self-management coping strategies than patients attending rheumatology services [10]. The nurse consultant-led pain management clinic study included support for ongoing self-management via an individual needs assessment and goal planning [57]. In comparison, Zih reported that only 30% of their rheumatology patients had used non-pharmacological strategies (for example, cognitive behavioural therapy or exercise), either on advice by staff or as pro-active choice self-reported by patients [78].

In relation to healthcare usage, Ryan reported that following assessment at a nurse consultant-led chronic pain clinic, visits to hospitals and general practices declined for the majority of patients within a three-year and one-year follow up period respectively [57]. Only Ryan detailed the length of care provision to patients; 80% of patients were discharged from the nurse-led clinic to their general

practitioner with a management plan, with a further 12% re-assessed after three months. Those with mental health concerns (8%) received longer support [57]. Co-existing mental health issues were also associated with increased healthcare usage in other studies [47,50]. The highest number of visits to different healthcare professions in the previous three months were observed in patients accessing psychiatrists (median: four, range: 2-33) [47].

3.2. Patient care experiences

A total of 22 studies were eligible for inclusion (Figure 1). This included 2,776 patients with fibromyalgia from 13 countries (eight European countries, three from the Americas and one each from Africa and Asia). Study designs included three quantitative, 16 qualitative and three mixed methods studies. Studies recruited participants within and outside of healthcare 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 exception of one specifically focused on male patients. Where ethnicity, age and symptom duration were reported, mostly white populations aged from 18 to over 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 healthcare professionals during the diagnostic process and ongoing care

[18,20,28,29,33,44,67,69]:

“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” [22]

Many patients acknowledged tensions between their expectations of healthcare and what is practicably deliverable within resource constraints; for example, the pressures experienced by healthcare professionals [51]. Hence, they tried to book only necessary appointments and/or prepare for their healthcare appointments [20,21,28,29,51].

However, a common thread across studies were 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 healthcare professionals and time-consuming healthcare appointments [10,15,18,21,30,44,51,69]. Patients reported that this diagnostic process often took years [15,16,20,30,69]. A diagnosis did not automatically mean that patients felt relieved [10,20,23,41,67]. Some patients said that they wished further diagnostic testing as they found the fibromyalgia diagnosis hard to accept [44].

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 [18,20,30,41,51]. A lack of coordination, poor continuity of care and limited support offered by healthcare professionals were reported [6,15,18,29,30,41,51,67]. Patients with fibromyalgia found these experiences frustrating and concerning:

"So many different physiotherapists have been involved, at least 10–15, all trying their own various methods – this is very tiring and doesn't lead to any overall improvement (2)." [51]

These experiences reportedly made it difficult to build relationships with or gain confidence in healthcare professionals, led to exhaustion and hindered improvement of patients' quality of life [30,51]. In comparison, nurse-led support for self-management was seen as valuable by some

patients with fibromyalgia [70]. However, Lempp identified an absence of regular nursing input for patients [41].

Patients often felt that healthcare professionals focused on their disease instead of seeing them as a whole person [67]. They reported limited knowledge by healthcare professionals regarding fibromyalgia [15,23,28,69]. Patients believed that both lack of knowledge and appointment times impacted on the ability of healthcare professionals to diagnose fibromyalgia, ensure early treatment and engage appropriately during consultations [15,29,30,51]. Patients also reported insufficient sharing of information and/or explanations relating to the condition [18,20,41]. How information was communicated was perceived to be as crucial as the provision of such information. These experiences reportedly led to confusion, anxiety, hopelessness, non-adherence to treatment and seeking alternative therapies [18,19] or information outside of the healthcare system [21,41].

Patients in both publicly funded and private-insured based healthcare systems experienced issues accessing care. In several studies, patients with fibromyalgia reported high personal costs related to medical care [15], such as attending clinic visits and private treatments [6,15,21,22,67]. 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.” (Patient 2) [15]

These financial factors affected their ability to receive ongoing care and pro-actively self-manage their condition to achieve a better quality of life. This was of huge concern to patients. Patients identified the structural root of the problem to be limited financial resources within the healthcare system [51]. Whilst private insurance could increase access to healthcare services, it appeared that only a minority of people had access to this [19]. However, even with private insurance there was no guarantee of long-term access to care.

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 healthcare journey and gaps in care. Resources made available across healthcare systems, and specific care settings within these, shaped interactions between healthcare professionals and patients, as well as access to care. At the same time, healthcare 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 healthcare professionals, inadequate sharing of information, and insufficient consultation times [6,16,18,20,22,28,30,41,51,67,69]. Patients preferred open and patient-centred communication styles by healthcare professionals that allowed reciprocal information sharing, increased mutual understanding and encouraged shared decision-making about care [9,21,22,68]. Feeling accepted as a person by the healthcare professional was rated as important [19], potentially even more important than time and medical knowledge of the healthcare professional [8]. Patients offered clear ideas on how healthcare professionals could improve their care:

- Allow patients' experiences, expertise and needs to be heard, then involve them accordingly
- Acknowledge fibromyalgia as a condition which requires people to receive healthcare support
- Increase their knowledge about fibromyalgia-related issues while being honest about gaps in knowledge
- Direct patients to suitable support if appropriate
- 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 healthcare system, coordinated care, as well as continuity of care by a single healthcare professional and across healthcare services [6,15,18,30,51,70]. Many patients desired ongoing commitment and support by healthcare professionals other than medication prescriptions. Examples included providing 'moral support', problem-solving and support for self-care as well as employment and relationship concerns [15,30,67,70]. However, we did not identify any study which specifically explored patient preferences for care.

Patients thought that a range of services for fibromyalgia should be accessible within the healthcare system, including psychological support and rehabilitation. They specifically asked for multi-disciplinary fibromyalgia specialist clinics [6,15,30]. Health information technology was seen by patients as another useful way to increase accessibility to care for fibromyalgia [62,70]. However, whilst 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 healthcare professionals [62].

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 healthcare encounters appeared to dominate these experiences. Patient needs such as supportive attitudes by healthcare 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 healthcare system. Including all study designs produced a more comprehensive, refined picture of current healthcare delivery for fibromyalgia. Interestingly, no single research article was identified which specified the use of patient reported experience measures. However, the review process posed a challenge with no standard definition of a model of care available [54]. 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 healthcare journeys and highlight key care gaps. Further, 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 was deemed useful for answering the review questions was 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 healthcare 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 healthcare 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 healthcare professionals, fibromyalgia is a contested illness [52] and how patients are viewed by healthcare systems can influence care provision [36,64]. A substantial number of healthcare 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 [36,37,52]. 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' [3]. This complexity presents a specific challenge to healthcare, which is further compounded by a lack of evidence-based guidelines to inform how best to organise and deliver multi-disciplinary care for fibromyalgia. Consequently, a number of issues become even more important and are outlined below.

Effective patient-healthcare professional relationships represent a core foundation of healthcare and have been demonstrated to have a positive impact on patient outcomes [66,74]. Building strong relationships is a mutual process, requiring investment from patients and healthcare professionals alike. The review showed that positive experiences with healthcare providers make patients feel better informed, supported and more satisfied at any stage of their healthcare journey. However, difficult encounters with healthcare 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 [49,59].

Fibromyalgia has a wide-ranging impact on people's lives (such as increased risk of mortality and reduced workability) [19,42,56]. 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 multi-disciplinary care and life-course approach is needed [1,2,5,17,40,43,63]. . However, this requires coordination of care across care providers (including with community, third sector or government services) and follow up (for example, 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 healthcare 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 [7,26,72], would be another valuable addition to the multi-disciplinary team. Nevertheless, our review showed a lack of evidence regarding nursing input (except two 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 healthcare professionals, what works best for them. However, the ability of individual patients to make decisions and access healthcare successfully will ultimately be influenced by the organisational and funding set up of individual healthcare systems. Primary care has potential to improve healthcare delivery to those living with fibromyalgia. For example, Lee acknowledge the unique strengths of primary care regarding its knowledge about the populations they serve, the provision of person-centred, comprehensive care (including chronic and co-morbid conditions), early intervention, continuity of care, and established patient relationships [40]. Primary care is also well placed to support coordination, integration of and collaboration with multiple care providers, and strong organisational relationships [65,74]. Primary care also provides the first contact for patients with the healthcare system in many countries and is normally more cost-effective than secondary and specialist care [65]. 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 [5,32,53].

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 healthcare 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. Further, patient care perspectives are part of the

evidence base for improving quality of care [77]. The review findings provide insights that may help to improve service delivery for people with fibromyalgia. Firstly, healthcare 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 pro-actively patients' perspectives. Secondly, 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 healthcare utilisation and improved health and work outcomes. Thirdly, healthcare 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 multi-disciplinary, holistic care, in collaboration with third sector/non-government organisations, within different healthcare systems and the constraints which they pose. Whilst 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 versus condition-specific issues. We also recommend future reviews into patient experiences of specific treatments and the perspectives of healthcare professionals.

In conclusion, our reviews reveal there is little evidence on how best to organise and deliver care for fibromyalgia across the whole healthcare 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. Healthcare 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 healthcare providers.

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Figure

Figure 1. Identification and selection of included articles.

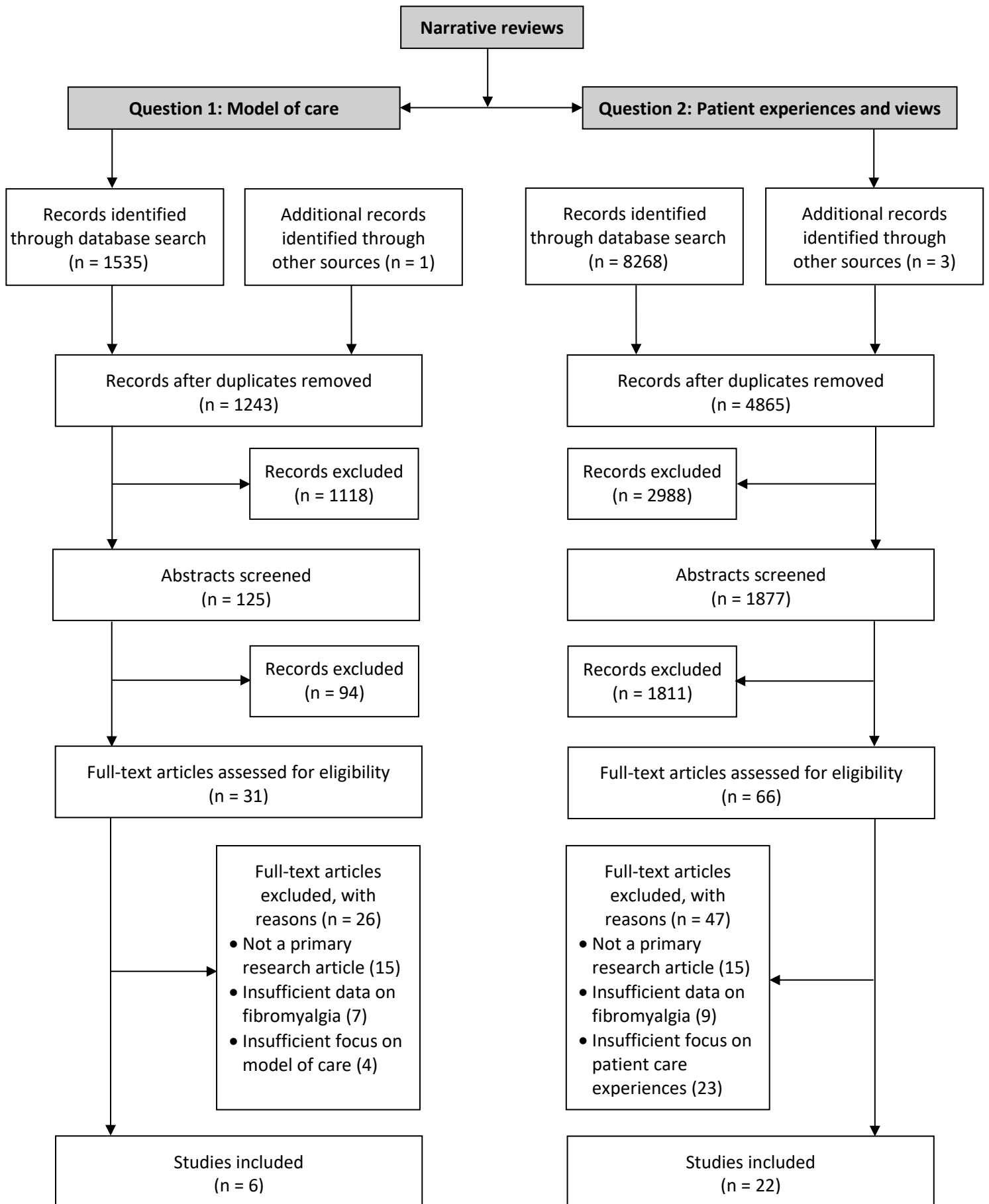


Figure 1. Identification and selection of included articles.

Table 1. Brief overview of included studies– review: model of care.

First	Ye	Country	Study design	Care setting	Healthcare
Boyer et	20	Spain	Cross-sectional study	Primary care,	Ongoing Care
Kroese	20	The	Randomised	Secondary/specialist	Diagnosis
McNett	20	United	Cross-sectional study	Primary care,	Ongoing Care
Mohanty et al.	2016	United States	Cross-sectional study	Primary care, secondary/specialist care, complementary	Diagnosis, Ongoing Care
Ryan et al.	2012	United Kingdom	Retrospective evaluation	Secondary/specialist care, complementary care	Assessment, Ongoing Care
Zih et al.	20	Canada	Retrospective chart	Secondary/specialist	Diagnosis,

Table 2. Brief overview of included studies (experiences of care, preferences for care and identified

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 years 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 three groups Age: 51-52 (mean) across three cohorts Symptom duration: NS	Secondary/specialist care	To examine the impact of a shared decision-making intervention regarding encounters between patients and healthcare professionals
Boulton (2018)	Canada, United Kingdom	Qualitative interviews	N=31 (female 81%) Age: 43 years (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 years (mean) Symptom duration: NS	Peer support	To identify potential care provision issues from the perspective of patients and healthcare professionals by examining three 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 years (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.	Mexico	Qualitative interviews, fieldwork observations	N=8 (female 63%) Age: range 34-74 years	Secondary/specialist care	To explore the encounters between fibromyalgia patients and rheumatologists based in Mexican public hospitals and private clinics

al. (2016)			Symptom duration: range less than 1 year to 10 years		
Cooper et al. (2017)	South Africa	Qualitative interviews	N=15 (female 100%) Age: range 23-59 years 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 years (mean) Symptom duration: 14 years (mean)	Peer support, other	To explore fibromyalgia patients' strategies of interacting with the healthcare system
Cunningham et al. (2006)	Canada	Qualitative interviews	N=8 (female 88%) Age: range early 30 to late 70 years Symptom duration: range 18 months to 13 years	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 years (where specified)	Peer support	To explore participants' broader understanding and experiences of fibromyalgia including diagnostic concerns
Durif-Bruckert et al. (2014)	France	Qualitative interviews	N=35 (female 91%) Age: 49 years (mean) Symptom duration: 5 years (mean)	Secondary/specialist care	To understand fibromyalgia patients' experiences with medications and its impact on the relationships with their doctors
Egeli et al. (2008)	Canada, United States, United Kingdom	Qualitative survey	N=42 (female 93%) Age: 47 years (mean) Symptom duration: 16 years (mean)	Peer support, other	To explore patients' interactions (positive and negative) with healthcare professionals
Escudero-Carretero et	Spain	Qualitative focus groups	N=21 (female 95%) Age: range 33-62 years	Healthcare (NS), peer support	To understand the experiences and expectations of fibromyalgia patients regarding the healthcare system and healthcare professionals

(al. 2010)			Symptom duration: range 2-40 years		
Golden et al. (2015)	United States	Cross-sectional study	N=1,228 (85%) Age: 51 years (mean) Symptom duration: NS	Other	To enhance care provision for fibromyalgia patients
Lempp et al. (2009)	United Kingdom	Qualitative interviews	N=12 (female 92%) Age: 49 years (mean) Symptom duration: 3 years (mean)	Secondary/specialist care	To enhance care provision for patients with fibromyalgia
Madde n et al. (2016)	United Kingdom	Qualitative interviews	N=17 (female 94%) Age: range 25-55 years Symptom duration: NS	Secondary/specialist care	To explore fibromyalgia patients' experiences of the diagnostic process
Paulson et al. (2002)	Sweden	Qualitative interviews	N=14 (female 0%) Age: range 41-56 years Symptom duration: range 4-24 years	Secondary/specialist care	To explore healthcare experiences of male patients with fibromyalgia in Sweden
Sparks et al. (2015)	United States	Mixed method study	N=35 (female 91%) Age: 51 years (mean) Symptom duration: NS	Secondary/specialist care	To assess the feasibility of integrating a self-management tool into clinical practice by incorporating patient views
Thorne et al. (2004)	Canada	Qualitative interviews	N=11 (female 91%) Age: range 21-76 years Symptom duration: minimum 5 years	Peer support, other	To explore helpful and unhelpful communication patterns with healthcare professionals from the perspectives of people living with fibromyalgia
Ullrich et al. (2014)	Germany	Cross-sectional study	N=256 (female 91%) Age: 53 years (mean) Symptom duration: range less than 1 year to more than 10 years	Secondary/specialist care	To investigate fibromyalgia patients' communication preferences in comparison to other chronic diseases
Undeland et	Norway	Qualitative focus groups	N=11 (female 100%)	Peer support	To investigate participants' positive and negative experiences

al. (2007)			Age: range 42-67 years Symptom duration: range 8- 40 years		regarding their fibromyalgia diagnostic journeys
Vander boom et al. (2014)	United States	Mixed method study	N=20 (female 100%) Age: NS Symptom duration: NS	Secondar y/ 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