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## **PATIENT-PERCEIVED HEALTH SERVICE NEEDS IN INFLAMMATORY ARTHRITIS: A SYSTEMATIC SCOPING REVIEW**

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## ABSTRACT

**Background:** Care that is patient-centred is more likely to be sustainable and associated with improved health outcomes. This approach to care requires an understanding of patients' health service needs, yet few studies have directly investigated the perceived health service needs of people with inflammatory arthritis.

**Objectives:** To systematically identify the existing literature relating to patient perceived health service needs for inflammatory arthritis.

**Methods:** A systematic review of MEDLINE, EMBASE, CINAHL and PsycINFO was conducted (1990–2016). Studies examining patients' perceived needs relating to health services for inflammatory arthritis were identified. Descriptive data regarding study design and methodology were extracted and risk of bias assessed. Findings were collated and categorized thematically.

**Results:** 27 of 1405 (16 qualitative, 9 quantitative and 2 mixed-methods) studies were relevant. The main areas of perceived need related to 1) Communication: consumers wanted clear, empathic communication and to be involved with decision-making. 2) Characteristics of ongoing care: adequate consultation length with continuity and timely care were valued. 3) Factors influencing care-seeking included individual attitudes, disease severity, finances and family expectations. 4) Allied health and complementary and alternative medicines (CAM) were perceived as useful by many. The reporting of CAM use to doctors was variable, with several factors contributing to under-reporting.

**Conclusions:** This review identified patients' perceived needs for better communication with their health providers, the heterogeneity of influences determining when care is sought and preferences regarding non-pharmacologic therapies. Aligning patients' perceived needs with evidence based therapy for people with inflammatory arthritis will be important in optimizing patient outcomes.

**KEY INDEXING TERMS:** Inflammatory arthritis, rheumatoid arthritis, ankylosing spondylitis, health services, complementary and alternative medicines, systematic review, patient-centered care.

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**Significant findings:**

- Identification of patient priorities for management and follow-up of inflammatory arthritis
- Identification of current gaps in understanding of patient preferences for inflammatory arthritis care

Accepted version

## BACKGROUND

The inflammatory arthritides are a heterogeneous group of diseases associated with significant morbidity, mortality and healthcare costs.(1) Appropriate clinical management has been shown to improve health care outcomes, limit significant interference with function and ability to perform daily activities and improve quality of life.(2-4) Indeed, the main things patients aim to achieve from treatment are pain control and maintenance of independence.(5, 6) Much of the focus of clinical research and practice is centered around the pharmacologic treatment and use of biologic agents to control disease activity in inflammatory arthritis (i.e. a clinician or disease activity-centred approach to care). However, the importance of care that is meaningful to, and desired by, patients (i.e., a patient-centred approach to care) is increasingly recognized as critical to forming effective therapeutic relationships, supporting self-management, and improving satisfaction with care and health outcomes.(7, 8) For this reason, a 'patient-centred' approach to care is now accepted as a fundamental component of models of care, clinical guidelines, and a guiding principle of healthcare safety and quality.(9-13)

Patient-perceived healthcare needs have been explored in various chronic diseases, for example palliative care,(14) oncology(15, 16) and diabetes.(17) In these conditions, emergent themes include a preference for shared-decision making, the need for psychosocial and information support, and positive relationships with healthcare providers. A number of studies have demonstrated the positive effects of patient-centered care on patient adherence to treatment, outcomes, satisfaction and healthcare-associated costs in non-musculoskeletal conditions. (18-27) A key question is why should these patient-centred components of care and outcomes be any different in the context of inflammatory arthritis? Relative to the vast majority of chronic health conditions that are more prevalent with ageing, inflammatory arthritis typically affects younger people, most often when their careers, relationships and families are commencing.(28) The impact of the inflammatory arthritis at these critical life stages are therefore likely to be somewhat different to other health conditions experienced by older people and as such, patients' expectations from health services may differ.

While there are numerous studies, which have reported factors that are perceived as important to patients (or 'needs') in the management of their inflammatory arthritis,(28) a systematic identification and appraisal of these data has not been undertaken previously; this has been identified as a priority(29) and an essential first step towards optimizing the use of often limited health resources. One of the most important domains of patient-centered care is determining the patient's perspective as it related to their perceived needs from health services.(29) This is particularly important in the context of emerging models of care for inflammatory arthritis.(30) Further, although the management of inflammatory arthritis aspires to deliver patient-centered care,(31) the existing literature regarding patients' perceived health service needs has not been examined systematically. As such, the totality of evidence around patients' perspectives remains unclear, suggesting a need for a systematic identification and appraisal of this broad literature.

Therefore, the aim of this systematic review was to identify and synthesise the existing literature regarding these patient-perceived health service needs relating to inflammatory arthritis. While this review does not aim to be a primary, patient-centred

study, we sought to identify evidence where patients' perspectives, captured either quantitatively or qualitatively, were reported, so as to provide a reliable of summary of patient self-report data.

## **METHODS**

Our review question was intentionally broad in order to synthesise a predicted wide breath of literature relating to patients' health service needs. As such, we adopted a scoping review approach to conduct the review, as described by Arksey and O'Malley,(32), underpinned by systematic review principles for evidence identification and analysis. This approach was performed to capture the breadth of the topic to enable a comprehensive exploration of the patients' perspective, map the existing literature and to identify gaps in the evidence.(33, 34) This review formed part of a larger project examining patients' perceived needs relating to musculoskeletal health more generally (35).

### *Search strategy and study selection*

Four relevant databases (CINAHL, EMBASE, MEDLINE and PsycINFO) were electronically searched between January 1990 and July 2016 combining both MeSH terms and text words to capture evidence regarding patients' perceived health service needs (defined as self-reported expectations, desires or requirements) relating to inflammatory arthritis. The concept of "need" is complex and multidimensional and a consensus definition of this concept is currently lacking.(29) Scholars have, therefore, suggested that within the context of exploring health-related needs, studies should focus on what patients desire or expect to receive from health services.(29) Our operational definition aligns with this recommendation around scope of the concept and its specificity to health services.

A comprehensive search strategy to identify evidence relative to needs related to health services was developed iteratively by a multidisciplinary team involving clinician researchers (Rheumatologists and Physiotherapists), a patient representative and an academic librarian. The detailed search strategy is provided in Appendix 1, which identifies the explicit components we included in our conceptual definition of 'patients' needs'.

Studies were not excluded based on study methods to capture the breadth of the topic. Importantly, we specifically included qualitative studies in our eligibility criteria as we anticipated these studies would provide the richest data on patients' perspectives, given the manner in which qualitative data are collected.

One investigator (JS) screened the retrieved titles and abstracts using open-ended screening to retain as many relevant studies as possible. Only full text studies written in English were included. The abstracts of retained articles were assessed to determine whether they met the inclusion criteria. Studies were included if they met the inclusion criteria: 1) Studies had to concern patients older than 18 with rheumatoid arthritis or other inflammatory arthritis; 2) Studies had to report on patients' perspective 3) studies had to relate to patients' perceived needs, encompassing expectations, desires and requirements related to non-pharmacologic health services, including conventional medicine, allied health and complementary and alternative medicines and therapies (CAM); 4) Studies had to concern inflammatory arthritis,

predominantly. A manual search of the reference lists of the obtained studies was conducted to identify further studies for inclusion in the review. The full text for articles that appeared to meet inclusion criteria were retrieved and assessed for relevance (JS).

#### *Data analysis and synthesis*

One investigator (JS) extracted the data from the included studies using a standardized extraction form developed for this scoping review. Studies were described according to their participant source and demographics, study design, primary aim and year published. The principles of meta-ethnography were used to synthesise the data(36). In the first stage, one author (JS) initially developed a framework of concepts and underlying themes, based on primary data in the studies and any pertinent points raised by the authors in the discussion. In the second stage, two senior rheumatologists (FC, AW) with over 15 years of consultant experience independently reviewed the framework of concepts and themes to ensure clinical meaningfulness and face validity.

#### *Quality assessment*

Two reviewers (JS, KC) independently assessed all studies for the likelihood of bias and methodological quality. Qualitative studies were assessed using the Critical Appraisal Skills Program appraisal tool(37). Quantitative studies were assessed using a modified incidence/prevalence study tool designed to identify bias created by Hoy et al.(38) For quantitative studies, low risk of bias was defined as scoring 8 or more “yes” answers, moderate risk of bias was defined as 6 to 7 “yes” answers and high risk of bias was defined as 5 or fewer “yes” answers. Differences were resolved by discussion. If no agreement was reached, a third reviewer adjudicated (AW).

## **RESULTS**

### **Overview of included studies**

The search strategy returned 1405 papers of which 27 manuscripts met the inclusion criteria for this review. A PRISMA flow diagram demonstrates selection of papers in more detail in Figure 1. The descriptive characteristics of the included studies are shown in Table 1. Most of these studies involved only people with Rheumatoid Arthritis (RA) (19/28).(5, 39-56) Inclusion criteria for these studies was RA defined either by ARA (American Rheumatology Association) criteria,(5, 45, 46, 49, 52-54) by a rheumatologist,(39-42, 47, 48), by ICD-10 coding,(56) or by unspecified criteria.(43, 44, 50, 51, 55) Two studies included mostly patients with RA,(57, 58) while three studies included either undefined or a smaller proportion of patients with RA combined with musculoskeletal conditions including osteoarthritis (OA), fibromyalgia, polymyositis or unspecified inflammatory arthritis.(59, 60) One study contained an unspecified number of patients with psoriatic arthritis in a population of patients with psoriasis,(61) two studies included a majority of patients with unspecified inflammatory arthritis(62, 63) and one study included patients with “chronic arthritis” of unspecified aetiology.(64)

Most studies were from the UK(40, 42, 44, 46-51, 53, 57, 62, 63), Europe, (5, 52, 54-56, 59), Northern America(39, 43, 58, 60, 61, 64) and the Asia-Pacific region(41, 45).

Participants were recruited predominantly from hospital outpatient clinics,(5, 39, 40, 42, 45, 46, 53-55, 57, 58, 60, 62, 63) private or community rheumatology clinics,(41, 43, 47, 49-51) and databases.(48, 52, 56, 61)

There were 16 qualitative studies,(5, 40, 42-44, 47-51, 53-55, 57, 58, 63) 9 quantitative studies(39, 41, 45, 52, 56, 60-62, 64) and two mixed-methods studies.(46, 59) Most of the qualitative studies were performed using focus groups or semi-structured interviews,(5, 40, 42, 44, 46-51, 53-55, 57-59, 63) while all quantitative studies utilized questionnaires.(39, 41, 45, 46, 52, 56, 59-62, 64)

Participant numbers in qualitative studies ranged between 5 and 88. The mean age range for participants was 46 to 60, 45 to 100% of female participants. Quantitative studies' included between 101 and 5604 participants, with the mean age ranging between 55 and 68 years. The percentage of female participants ranged between 60 and 86%.

### **Risk of bias in included studies**

Quality assessments of the included studies are presented in the Supplementary Appendix, Tables 3 and 4. Many of the qualitative studies had risk of bias associated with data collection,(5, 43, 44, 48, 49, 53, 54, 57-59) recruitment strategies(40, 44, 49, 51, 53-55, 57-59, 63) and researcher bias.(5, 42, 43, 47-49, 51, 53, 55, 57-59) Risk of bias in the quantitative studies mainly related to representativeness of study populations,(39, 41, 45, 52, 59, 60, 62) non-response bias,(39, 41, 52, 56, 59-62, 64) validity of measurement tools(41, 45, 56, 59-62, 64) and adequate study follow-up time.(39, 41, 52, 60-62, 64)

### **Results of review**

The themes identified in the search are summarized in Table 2. The three key themes identified included communication and desired characteristics of health professionals, aspects of follow-up care, factors relating to care seeking and allied health and CAM use.

### **Patients' perceived needs related to communication**

Nine studies focused on patients' perceived needs related to communication and the relationship between patients with inflammatory arthritis and their healthcare practitioners.(5, 43, 47, 49, 50, 53, 55, 57, 63)

#### *Characteristics of healthcare provider seen to be important by patients*

In all of these studies, a holistic and positive consultation with healthcare providers was valued. Attributes important in healthcare interactions included empathy, understanding attitudes and feeling listened to.(47, 49, 53, 57, 63) A good relationship with healthcare providers was important to many patients,(5, 43, 53) while a holistic approach was also often favoured.(50, 57, 63)

#### *Need for clear communication*

The importance of clear explanations and provision of information, particularly regarding their disease, investigation results and treatment options, was important to many participants.(47, 53) Many patients expressed frustration at perceived "mixed messages" regarding the provision of information from their healthcare

practitioners.(47)

*Patients' need to be involved in decision making*

The desire to be involved in decision-making was identified in five studies. Participants valued feeling listened to, being actively involved in decision-making, being offered different treatment choices and the ability to lead conversations. Barriers to shared decision-making included the perception of doctors not taking their problems seriously, not being offered a role in decision making and sub-optimal understanding of the information surrounding particular decisions. (5, 47, 50, 53, 55)

*Patients' need to gain information by sharing experiences with other patients*

Two studies identified patients with RA who expressed a desire for the opportunity to share experiences with other patients. The exchanges between patients regarding their disease and treatments were felt to have great potential for emotional and psychological support between patients. (47, 50)

*Accessing electronic health records*

A study by Van der Vaart(52) explored the benefits of patients accessing their own electronic medical records, with some perceived benefits including feeling involved and improving the quality of their care.

**Patients' perceived needs related to various aspects of follow-up care**

Patient-perceived needs related to the operational aspects of care in clinics were explored in nine studies, particularly the type of follow-up care, access to healthcare professionals and length of time allocated for consultations.(5, 47-50, 53, 56, 57, 62)

*Length of consultation*

Three studies identified a desire for an adequately long consultation.(47, 49, 57) Many patients were also unhappy with perceived inadequate consultation time with practitioners, particularly disliking when the consultation felt rushed or inadequate.(47, 49, 57) This was of particular dislike in secondary care.(57)

*Preferences for follow-up care*

Two studies reported a preference for follow-up by a specialist for inflammatory arthritis.(57, 62) In two studies, patients highlighted the importance of having sufficient access and choices with regards to rheumatology follow-up,(5, 50) while continuity of care was identified as an important aspect of follow-up care.(57) In a mixed cohort of rheumatology patients from the UK, Douglas expressed a much stronger preference to have follow-up care in a local hospital outpatient clinic rather than with primary care providers.(62). Although Arthur(57) did not specifically explore patients' preferences for type of follow-up care, patients who were in both primary and secondary care follow-up were mostly satisfied with the care they were receiving. Unlike participants in primary care, participants in secondary care prioritized "specialism" with regards to their arthritis care.(57)

*Timing and accessibility of appropriate care and in times of need*

Three studies identified the need for the provision of timely care.(47, 49, 53) Patients valued the importance of having access to their practitioners in times of need between follow-up appointments.(49, 53) Many patients expressed frustration at long wait



times for investigations and to see practitioners, valuing clinics that ran efficiently to reduce these wait times.(47, 49, 56) Pollard(49) identified patients who were frustrated with perceived delays in referral for specialist management of their disease.

### **Perceived need to seek and access care**

Factors influencing the patients' perceived need to seek health care were explored in nine studies.(39, 40, 42, 43, 46, 48, 56, 59, 61)

#### *Patient related factors*

Seven studies explored patients' perceived barriers and predictors of care seeking.(39, 40, 42, 43, 46, 48, 61) Increased age was associated with increasing health care seeking behaviour(43). Previous negative experiences with medical consultations(39) discouraged care seeking, exemplified by those with psoriatic arthritis, as they had "given up".(61) Other patients delayed seeking care from clinicians based on misattributing or ignoring their symptoms,(46, 48) belief that seeking specialist care may negatively influence treatment,(40) or thought that medical practitioners should be the last resort.(42)

#### *Disease related factors*

Disease factors were explored in three of the studies.(42, 43, 61) Higher disease activity was found to be a predictor of care seeking in two of the studies.(42, 61) Fraenkel(43) found that patients who were minimally or severely impacted by their disease were not open to treatment alternatives (even if they were clinically warranted), while patients who were moderately impacted by their disease were more open to treatment alternatives.

#### *External factors*

Eight of the studies explored external factors that influenced care seeking.(40, 42, 43, 46, 48, 56, 59, 61) Having insurance was a predictor of physician visits. Financial or funding issues were identified as significant impediments to accessing health care.(40, 48, 56, 59, 61) Family members were influential in care seeking behavior, although the direction of effect was not consistent: some advocated for care seeking,(42, 46) while other family members did not.(46) Other external factors which were perceived to affect access of healthcare included location of services,(59) misdiagnosis by healthcare providers(48) and patients' role responsibilities within their families.(40, 43)

### **Need for allied health and CAM**

There were seven studies that investigated CAM use in patients with inflammatory arthritis,(41, 44, 45, 51, 58-60) which primarily explored the different types, frequency and reasons for using CAM. There were two studies that investigated use of allied health services.(54, 64)

#### *Utilization and perceived need for allied health services*

Feldman(64) found a low referral rate to physiotherapy and occupational therapy in chronic arthritis, although most patients who felt they required these services received them (96%). Neiderman(54) found the use of joint protection strategies was perceived by patients to improve pain, function and psychological wellbeing, but barriers to implementation were mainly the time and effort required, as well as potential embarrassment when using these strategies.

### *Perceived need for different modalities of care*

The prevalence of patients who had ever used CAM ranged from 60 to 76%.(41, 45, 59, 60) The most commonly used forms of CAM therapies were dietary supplements,(41, 45, 51, 58-60) manual therapies (e.g., chiropractic, massage)(41, 59, 60) and topical treatments.(41, 58) There were many other modalities less frequently utilized including prayer, acupuncture, mind-body therapies (e.g., meditation, relaxation) and electrical stimulators.(51, 58)

### *Perceived benefits, motivations to use and predictors of CAM*

The most commonly reported reasons for using CAM were symptom relief where conventional treatments were perceived to have failed,(44, 45, 51, 58, 60) and to complement conventional therapies in disease management.(58-60) Other reported motivators for use included the desire to minimize medication use and associated side effects, other negative experiences with conventional therapies and the belief that these modalities would cure their disease.(44, 51, 59, 60) Reported predictors of CAM use were female sex,(41, 45) younger age,(45) higher education,(59) and longer time from disease diagnosis,(45) although these were not consistent between studies.

## **DISCUSSION**

This review identified 27 studies(5, 39-64) that explored the patients' perspective relating to non-pharmacologic health service needs for inflammatory arthritis. While not a primary, patient-centred study, our review provides important secondary evidence of factors, reported by patients, which are perceived to be important in the management of their inflammatory arthritis in the context of health services. The health service needs identified mainly related to four areas: communication needs; follow-up care; accessing care and associated barriers; and perceived needs for allied health and CAM. Although many of these findings relate to the patient – health care provider relationship, some may have implications for provision of health care services and support for patients with inflammatory disease.

Patients identified needs related to a variety of aspects of communication. Patients valued positive interactions and relationships with their healthcare providers.(5, 43, 47, 49, 53, 57) Desirable qualities of healthcare provided included good listening skills, clear provision of information, an ability to empower patients and allowing enough time during consultation.(47, 49, 53, 57) These are all similar factors identified by patients with other chronic conditions, including diabetes,(17) oncology(15, 16) and palliative care,(14) and highlights patients' desire for patient-centred care. Given the well established gains in satisfaction, engagement and outcomes where patients have positive experiences with healthcare providers,(65) particularly in chronic disease,(27, 66-69) healthcare practitioners managing patients with inflammatory arthritis need to make a conscious effort to consider these issues in their practice.(28)

This review found many patients emphasizing the importance of seeing specialists and easy access to medical consultation in their arthritis care.(5, 57, 62) This was commonly motivated by perceived specialism and expertise of specialists in

managing the inflammatory arthritis.(57, 62) Other priorities relating to follow-up care included adequate consultation time, proximity of care, continuity of care and timely referral to specialists.(5, 47, 49, 53, 57) While both patients and clinicians identified the importance of accessing specialist care in times of need (e.g., disease flare), specialists have highlighted difficulties with time constraints and resource allocation as limiting factors to providing optimal care.(49) Given these barriers and the importance of early diagnosis and treatment of inflammatory arthritis,(70) there may be an important role for alternative models of care for healthcare delivery (such as community-based shared care services, up skilling of nurse practitioners, telehealth services, community-based centres and after hours services).(71) The implementation of these healthcare services may improve access and support for patients and provide more flexibility during disease flares or other times of need. Patients may require education around changes to models of care, to ensure that they are accepted, and used appropriately.

Access to health care services was identified as an important priority by patients. Patients perceived access to be hindered by factors related to themselves, their disease, and the health care system.(39, 40, 42, 43, 46, 48, 59, 61) Significant patient related factors that affected healthcare access included personal and family beliefs, previous experiences with healthcare professionals and financial considerations.(39, 40, 42, 43, 46, 48, 61) While, financial concerns are well-established barriers to healthcare seeking,(72-74) patients with chronic disease including inflammatory arthritis have increased disease-related healthcare costs, further attenuating their willingness to access to comprehensive care. This underscores the need for healthcare practitioners to be aware of the costs of care faced by the patient when determining management strategies. Addressing this issue is particularly important as delay in diagnosis and treatment increases long term overall disability and disease costs.

Many patients recognized an important role for allied health in the management of their inflammatory arthritis.(54, 64) However, this review found that referral by physicians to allied health professionals and subsequent utilization by patients was relatively low. It is possible that low utilization of allied health services may be due to financial considerations(75) or lack of widespread appreciation of the benefits of allied health services, with only 26% of participants in Feldman et al expressing a need for these.(64). This is problematic as there is good evidence supporting the use of non-pharmacological interventions including joint protection and patient education in improving outcomes in inflammatory arthritis.(76-79) Nevertheless, these studies support previous estimates of low allied health utilization and referral amongst patients with inflammatory arthritis.(80-82)

Many patients with inflammatory arthritis also use CAM therapies in the management of their condition.(41, 45, 51, 58-60) The most frequently reported CAM used were dietary supplements, which may reflect their ubiquitous use within the broader community.(83-85) Although the estimates for CAM use in the general population vary widely, previous studies have shown that use in inflammatory arthritis may be even higher, with up to 80% of patients reporting having ever tried these therapies.(41) This may not be surprising given the significant pain and other disability associated with inflammatory arthritis. Future research examining the role and efficacy of CAM are also warranted, particularly given their high level of use and patient interest, as well as their potential to interact with medical therapies.(86, 87)

This review was limited by the characteristics of available data. Most of the studies concentrated populations of people with RA. Although the prevalence of RA is higher than other inflammatory arthritides, only eight of the 27 studies included patients with other inflammatory arthritides.(57-64) Thus, the results from this review need to be generalized with care to other inflammatory arthritis, particularly as these may affect patients from different demographic groups. The country of origin was relatively limited, with studies only found from developed countries, with almost half from the UK, and may not be fully generalisable to other countries with different ethnicities, healthcare systems and payer models. Many of the studies preceded the widespread use of effective biological therapy, and may not reflect the current needs of patients with inflammatory arthritis. Finally, we acknowledge that the concept of patients' needs is multidimensional and complex.(29) Inherent in this complexity is the risk that different authors will apply different operational definitions for the concept of need. Such potential variability may result in not identifying some evidence where the definition of 'need' differed substantially to the one applied in this review. Nevertheless we have performed a broad scoping search of the existing literature, using a comprehensive search strategy that incorporated both qualitative and quantitative studies. The majority of identified studies utilized qualitative methods, which are suitable for exploring biopsychosocial paradigms and provide insight into patient beliefs and attitudes.

This review identified patients' desire for good communication with their health providers as well as exploring issues surrounding factors that influence their perception of need to access and use different healthcare services for their inflammatory arthritis. Aligning patient perceived needs with evidence for efficacy of therapies as well as healthcare resources in inflammatory arthritis will be important in optimizing patient outcomes. The extent of CAM use in the literature suggests that patient relevant outcomes are not being met by current management strategies. Whether this is due to ineffective therapy or a failure to address patient concerns is unclear and needs to be investigated given the potential for harm with some of these therapies. Policy makers and health care services may consider the use of novel models of care delivery, including telehealth services and specialist nurse practitioners and education which may help to provide more efficient care, improving accessibility, flexibility of care provision and patient satisfaction with the amount of time allocated to consultations.

In conclusion, we found that patients with inflammatory arthritis directly and indirectly expressed perceived needs regarding management of their inflammatory arthritis including positive healthcare relationships, convenient access to healthcare and the value of CAM. Further work will be needed to directly determine whether there are specific patient priorities for the management of inflammatory arthritis and the adequacy of their health systems to meet these needs. This may help better align patient and health care provider expectations, achieving better patient satisfaction at the micro-patient level, and improved health outcomes for those with inflammatory arthritis and the health care system at the meso and macro-patient level.

## **LIST OF ABBREVIATIONS**

ARA – American Rheumatology Association

CAM – Complementary and alternative medicines

OA – Osteoarthritis

RA – Rheumatoid Arthritis

## **DECLARATIONS**

### **Ethics approval & consent for publication**

Neither ethics approval nor consent for publication was required for this review.

### **Availability of data and materials**

All data analysed for this review are included in the published materials.

### **Conflict Of Interest Statement**

None to disclose.

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### **Authorship contributions**

AW, FC, MS & KS made substantial contributions towards the conception, design and acquisition of data for this study. JS and KC made significant contributions towards acquisition of data and analysis. All authors were involved in drafting the manuscript and revising it for critically important conceptual material. All authors have given approval for the final version of this review for publication.

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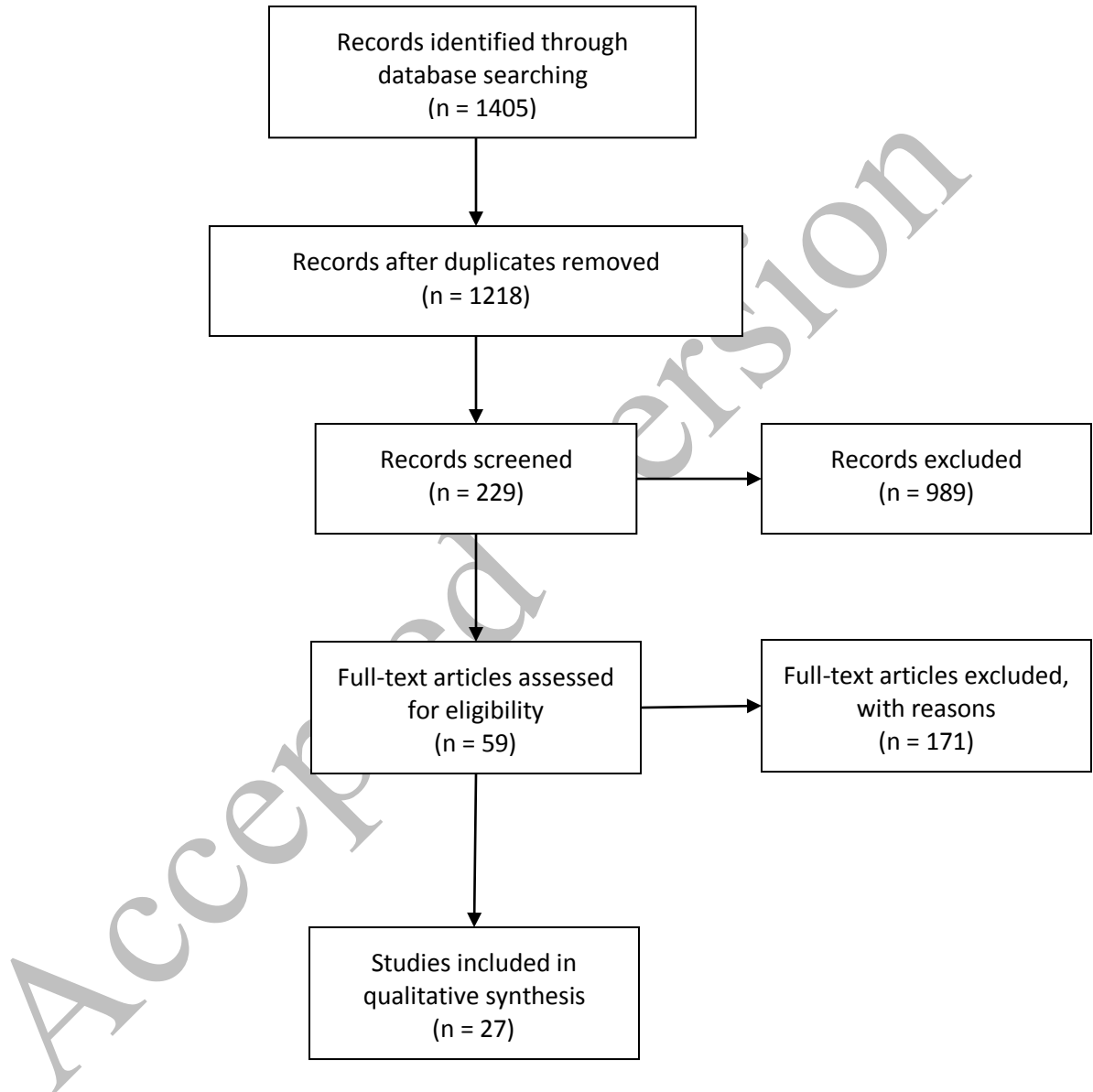
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**Figure 1: Modified PRISMA flow diagram**



**Table 1: Descriptive characteristics of included studies**

<b>Author (year) Country</b>	<b>Number of participants</b>	<b>Study type/design</b>	<b>Participant source</b>	<b>Age &amp; Gender</b>	<b>Diagnosis of inflammatory arthritis</b>	<b>Primary study aim</b>
Ahlmen (2005) Sweden	25	Qualitative; focus groups	Participants were recruited from 4 hospital outpatient rheumatology clinics	Median age 55; 64% female	RA (ARA criteria)	To explore important outcomes for patients with RA
Arthur (2004) UK	10	Qualitative; semi-structured interview	Convenience purposeful sample, 5 attending nurse led clinics (University Hospital Birmingham), 5 attending GP for follow up care (with Rheumatologist)	Age: 22-68; 70% female	9 had RA and 1 had polymyositis. Diagnostic criteria undefined	To identify the expectations and preferences of rheumatology patients for their follow-up monitoring care
Berkanovic (1995) USA	288	Quantitative; series of telephone interviews	Metropolitan Los Angeles, recruited from UCLA Medical Centre affiliated rheumatologists	33% <50 years old, 37% were 50 – 64 years old, and 29% were > 65 years old, 83% female;	Rheumatologists provided patients with “definitive or classical RA for at least 1 year”	To examine the factors affecting visits to physicians for patients with RA
Bhutani (2013) USA	5604, Unknown % with psoriatic arthritis	Quantitative; questionnaires	USA National Psoriasis foundation	Mean age 55; 60% female	Diagnostic criteria undefined for psoriasis or psoriatic arthritis.	Patient perceived factors affecting healthcare utilization and healthcare costs in psoriasis and psoriatic

						arthritis
Blake (2013) UK	9	Qualitative; semi-structured interviews	Local hospital rheumatology outpatient department	Mean age 58; 45% female	RA identified from medical records.	Factors affecting RA patients seeking podiatry services for foot care
Buchbinder (2002) Australia	101	Quantitative; telephone interviews	Two private rheumatology clinics	Mean age 61; 64% female	Clinically defined RA	CAM use in RA and possible predictors of use
Douglas (2005) UK	419	Quantitative; structured survey	All patients at outpatient rheumatology clinic in group of UK hospitals over 2 week period offered participation	Age 16 to 85 years old; 72% female	55% reported to have inflammatory arthritis, diagnostic criteria undefined	To explore patient preferences for rheumatology clinic follow-up
Dures (2016) UK	19	Qualitative; semi-structured interviews	Hospital outpatients department	Age range 27-75 74% female	Diagnosis of inflammatory arthritis, definition not specified	To explore the perspectives of patients attending those routine consultations to identify aspects of the interaction that influenced collaboration and self-management
Feldman (2010) Canada	211	Quantitative; structured survey	Patients recruited from primary care setting in Quebec, Canada	Mean age 68; 72% female	All patients were reported to have “chronic arthritis”. Aetiology and diagnostic criteria	To explore issues relating to access to physical therapy and occupational therapy

					unspecified	in chronic arthritis
Flurey (2013) UK	15	Qualitative; semi-structured interview	Patients recruited from outpatient RA clinics from 2 NHS trusts	Mean age 51; 80% female	Clinically defined RA.	To explore patients' experiences of daily life with RA on modern treatments
Fraenkel (2014) USA	88	Qualitative; think aloud protocol	Patients selected by rheumatologists from four community outpatient rheumatology clinics	Mean age 55; 74% female	All patients had RA but diagnostic criteria unspecified	Explore RA patients' approach to risk-benefit trade-offs in treatment choices
Hughes (2009) UK	13	Qualitative; unstructured and semi-structured interviews	Convenience sample of patients through stakeholder groups and various forms of advertisements	Mean age 60; unspecified gender	All patients had RA but diagnostic criteria unspecified	To explore experiences of treatment with acupuncture among RA patients
Ikuyama (2009) Japan	296	Quantitative; survey	Sample of patients attending a public rheumatology clinic at a university-affiliated hospital and a private clinic	Mean age 59; 84% female	RA (ARA criteria)	To determine the use of dietary supplements and health foods in RA patients
Jong (2012) Netherlands	416 in quantitative study, 10 in subsequent focus group	Mixed methods approach	Patients recruited through the internet and email (e.g., websites, stakeholder newsletters)	68% between age 50 and 70; 86% female	29% of participants had RA (diagnostic criteria unspecified). Other participants had other musculoskeletal disease including osteoarthritis and fibromyalgia	To explore CAM use and attitudes towards integration into primary care in musculoskeletal conditions

Kumar (2010) UK	10	Mixed methods; semi-structured interview for qualitative component	Patients of south Asian origin who had delayed seeking medical care prior to RA diagnosis at two large hospitals in Birmingham, UK	Median age 50. 90% female	Rheumatoid Arthritis (ARA criteria)	The influence of ethnicity and reasons for delay in GP consultation in RA patients
Lempp (2006) UK	26	Qualitative; semi-structured interview	Patients selected from two outpatient clinics in south-east England	Mean age 56. 85% female	Clinically defined RA	To explore RA patients' experiences of primary and secondary healthcare
Niedermann (2010) Switzerland	10	Qualitative; semi-structured interview, within mixed methods study	Convenience sample of 10 German-speaking patients from a university hospital outpatient rheumatology department in Switzerland	Mean age 58. 80% female	Rheumatoid Arthritis (ARA criteria)	To explore RA patients' and occupational therapists' perception of the benefits of and barriers to performing joint protection
Nota (2016) Netherlands	29	Qualitative; semi-structured interview	Patients were recruited from 2 hospital outpatient departments in the Netherlands	Mean age 56. 66% female	Patients diagnosed with rheumatoid arthritis, no diagnostic criteria specified	To gain insight into arthritis patients' motives for (not) wanting to be involved in medical decision-making and the factors that hinder or promote patient involvement
Oliver	22	Qualitative;	Participants recruited	Mean age 46;	Seropositive RA for 3	To explore the early

(2008) UK		semi-structured interviews	from members of the UK National Rheumatoid Arthritis Society	75% female	years or less	experiences of those with RA and compare these with benchmark standards and guidelines in the UK
Pollard (2011) UK	37	Qualitative; focus groups and interviews	Inner city Rheumatology outpatients. A representative sample of patients were selected into focus groups or face-to-face interviews from one inner-city hospital outpatient department	Mean age 57. 81% female	Rheumatoid Arthritis (ARA criteria)	Exploring patients' and healthcare providers' views on the barriers to integrated care in RA
Polluste (2012) Estonia	1237	Quantitative; questionnaire	Random sample of patients from Estonian Health Insurance Fund database	Mean age 59. 82% female	Rheumatoid Arthritis (ICD-10 criteria)	To explore the determinants of satisfaction with access to health services amongst Estonian patients with RA
Radford (2008) UK	12	Qualitative; focus groups	Participants selected from unspecified rheumatology nurse specialist clinic in the UK	Mean age 55; 83% female	All patients had RA but diagnostic criteria unspecified	To explore the professional supports patients receive and would have liked to have received upon diagnosis of RA



Rao (1998) USA	33	Qualitative; focus groups	Participants recruited from 3 outpatient clinical sites associated with Indiana University Medical Centre	RA patients: mean age 56; 70% female	23 of 33 participants had RA. Diagnostic criteria unspecified. The remainder had OA	To explore the use of CAM among patients with arthritis as well as reasons for use
Rao (1999) USA	232	Quantitative; telephone interview	Participants recruited from 6 outpatient sites: three university associated practices and three private practices	Mean age 56; 72% female	41% had RA (diagnostic criteria unspecified). The remainder had fibromyalgia, OA and other (unspecified) rheumatologic conditions	To identify predictors of CAM use among rheumatology patients and explore perspectives surrounding use
Rose (2006) UK	5	Qualitative; semi-structured interviews	Participants recruited from convenience sample of single rheumatology outpatient clinic in the UK	Mean age 50; 100% female	All patients had RA but diagnostic criteria unspecified	To explore the use of CAM among patients with arthritis as well as reasons for use
Van der Vaart (2014) Netherlands	214	Quantitative; questionnaire	Patients selected from an arthritis database in Twente, Netherlands	Mean age 62. 65% female	Rheumatoid Arthritis (ARA criteria)	To measure the use, satisfaction and impact of accessing medical records electronically among RA patients
Ward (2007) UK	25	Qualitative; semi-structured interview	Patients recruited from large teaching hospital in Yorkshire, UK	Mean age 57. 76% female	Rheumatoid Arthritis (ARA criteria)	Explore RA patients' perceived needs from outpatient visits

ARA: American Rheumatology Association; CAM: Complementary and alternative medicine; GP: General practitioner; ICD: International Classification of Diseases; NHS: National Health System; OA: Osteoarthritis; RA: Rheumatoid arthritis; UK: United Kingdom; USA: United States of America;

Accepted version

**Table 2: Patient perceived needs regarding health services**

<b>Author and year</b>	<b>Results</b>
<b>Communication</b>	
<i><b>Empathetic &amp; positive attitude, understanding in healthcare provider</b></i>	
Ahlmen 2005	A good relationship with healthcare providers was seen as important in increasing trust, mutual respect and reducing anxiety
Arthur 2004	Many participants valued practitioners with an empathetic and understanding attitude, as well as a holistic approach to the consultation (e.g., To be encouraged, to be listened to)
Dures 2016	Patients described the importance of clinicians' willingness to explore options and to be open to negotiation. They wanted clinicians to be understanding and particularly regarding the impact of the disease on their physical, social and emotional lives. Holistic clinicians were perceived as caring and attentive.
Fraenkel 2014	A good relationship and trust in healthcare providers were seen as important factors in considering treatment options
Lempp 2006	Empathy was identified as an important attitude for practitioners by patients
Pollard 2011	Many patients valued an understanding and empathetic approach by practitioners
Radford 2008	Patients valued having professionals to talk to and receive advice from upon diagnosis of RA. Some patients expressed the desire to be treated holistically by health professionals
Ward 2007	Most patients valued feeling listened to and having a positive relationship with their practitioner
<i><b>Clear communication</b></i>	
Lempp 2006	Many patients emphasized the importance of clear explanations for their disease, investigations and treatment options. Many were unhappy with conflicting messages regarding these elements.
Ward 2007	Most patients valued clear explanations from their practitioners (76%)
<i><b>Being involved in decision making</b></i>	
Ahlmen 2005	Participants considered themselves as experts in their own bodies and expected to be involved in the decision making process
Dures 2016	Patients felt they were better able to deal with their arthritis when they were actively involved in their care
Lempp 2006	Many patients felt it was important to be involved in decision making with practitioners answering questions, feeling listened to and offering choices being valued highly
Nota 2015	Patients preferred shared decision-making because it reflects a good relationship with the doctor. They felt that they

	could more easily participate in decision making when they are invited to do so, when they are taken seriously and being listened to and when the doctor is open to answering questions. Barriers to shared decision-making included perception of doctors not taking patients' problems seriously, not being offered a role in decision making and sub-optimal understanding of the information surrounding the particular decision.
Radford 2008	Many patients expressed the desire to be actively involved in decision making, with some lamenting the lack of these opportunities previously
Ward 2007	Most patients felt it was important to be able to lead discussions with their practitioners (72%)
<b><i>Sharing experiences with other patients</i></b>	
Lempp 2006	Some patients expressed a desire to have other RA patients as either volunteers or workers in their clinics
Radford 2008	Participants felt having other RA patients to talk to would be helpful for emotional support
<b>Aspects of care</b>	
<b><i>Length of consultation</i></b>	
Arthur 2004	Length of consultation was an important factor to many participants, particularly in secondary care
Lempp 2006	Many patients felt it was important for practitioners to give them adequate time for consultation, disliking when the consultation felt rushed or not thorough
Pollard 2011	Many patients were unhappy with perceived insufficient consultation time with practitioners
<b><i>Aspects of follow-up care</i></b>	
Ahlmen 2005	Convenient and choice regarding access to rheumatology care facilities was considered important to participants (e.g., location and time)
Arthur 2004	Continuity of care and adequate knowledge of the condition being treated were important factors to many participants
Douglas 2005	The vast majority of RA patients preferred to be followed up in secondary care (99.3%), while the majority of patients preferred to attend a clinic close to their home (75%). A majority had a preference for the day of the week on which follow-up occurred (53%), while morning appointments were also preferred (58%).
Radford 2008	Many patients highlighted the importance of having the choice of supports needed and access to these in times of need
<b><i>Timely care, accessible review, specialist referral and in times of need</i></b>	
Lempp 2006	Many patients expressed the desire to have reduced waiting times for practitioners and investigations. Many patients also valued efficient clinic staff and encounters with clinics.
Pollard 2011	Many patients were

	<ul style="list-style-type: none"> <li>• Unhappy with long wait times and delays in investigations and seeing practitioners. Many patients emphasized the importance of having support and access to practitioners during disease flares</li> <li>• Expressed frustration that they were not referred earlier to a specialist by their primary care physician in the initial diagnosis of their disease</li> </ul>
Polluste 2012	Satisfaction with access to health services was associated with shorter waiting times for doctors and shorter periods of time spent with doctors
Ward 2007	Most patients felt it was important to have access to their practitioners between scheduled appointments (72%)
<b>Perceived need to seek and access care</b>	
<b><i>Disease factors</i></b>	
Bhutani 2013	Greater disease severity was associated with greater number of physician and specialist visits
Flurey 2013	Flare symptoms often prompted many patients to seek care for their disease
Fraenkel 2014	Patients who were either very strongly impacted or minimally impacted by their disease were not open to alternative treatment options. Patients who were moderately impacted by their disease were more open to treatment alternatives
<b><i>Patient factors</i></b>	
Berkanovic 1995	Patients with negative attitudes to previous care were less likely to self-initiate follow-up
Bhutani 2013	For some patients, the effort of the consultation process was a barrier to seeking specialist care for their psoriasis and psoriatic arthritis (11%). Many patients also avoided follow-up for their disease as they had “given up” on it (27.6%).
Blake 2013	Some patients avoided seeking specialist foot care for their RA due to beliefs that this may negatively influence treatment decisions regarding their RA
Flurey 2013	Seeking medical care was often considered by participants as a last resort for symptoms
Fraenkel 2014	Age was seen by many participants as an important factor in considering treatment options
Kumar 2010	Many patients misattributed symptoms when delaying initial presentation for RA, while some either ignored symptoms or hoped they would go away with time or self-administered treatments
Oliver 2008	Delays for RA diagnosis and specialist referral included misattribution of symptoms by patients
<b><i>External factors</i></b>	
Bhutani 2013	Insurance coverage was associated with greater number of physician visits for psoriasis and psoriatic arthritis. Prohibitive cost was a common reason for not seeking specialist care (21%).
Blake 2013	Patients often avoided seeking foot care for their RA because of perceived material costs (eg. Money, time) and social costs (e.g., Did not want to appear a nuisance to family or healthcare team).

Flurey 2013	Many patients were encouraged by their family members to seek care for their RA
Fraenkel 2014	Role responsibility was seen as an important factor when considering risks and benefits of potential treatments for many patients
Jong 2012	One third of participants reported barriers to CAM use. Most commonly reported barriers included financial, lack of information and location of providers
Kumar 2010	Some patients were discouraged from seeking medical help by family members who misattributed symptoms, while some were encouraged to seek medical help. Many participants had family members only suggest complementary therapies for their symptoms. Many blamed a lack of knowledge for delaying healthcare seeking
Oliver 2008	Delays for RA diagnosis and specialist referral included misdiagnosis by primary care physicians. Some participants experienced delays in receiving treatments (despite eligibility) because of funding issues
Polluste 2012	Lower satisfaction with access to health services was associated with higher personal expenses for care, particularly expenses relating to medical consultations, transportation costs to see doctors and rehabilitation services
<b>Allied health and complementary medicine use</b>	
<i>Modalities used and prevalence of use</i>	
Buchbinder 2002	73% of patients had used some form of CAM and 32% had visited at least one complementary practitioner in the preceding year <ul style="list-style-type: none"> <li>The most common CAM and therapies included dietary (e.g. supplements, dietary alterations), exercise, topical products and massage</li> </ul>
Feldman 2010	26% of participants with chronic arthritis felt they required PT or OT; 96% of these participants received these services
Ikuyama 2009	60.5% of all participants were either current or recent users of dietary supplements (DS) <ul style="list-style-type: none"> <li>The most commonly used supplements were herbs, glucosamine/chondroitin, vitamins and minerals</li> </ul>
Jong 2012	76% of participants had used some form of CAM (i.e., Dietary supplements) or related therapies within the previous 2 years. <ul style="list-style-type: none"> <li>The most commonly used dietary supplements were homeopathic remedies, glucosamine, vitamins, herbs and fish oil</li> <li>The most commonly used CAM therapies were manual therapies (e.g., massage, osteopathy, chiropractic), acupuncture and mind-body therapies (e.g., meditation, yoga and tai-chi)</li> </ul>
Rao 1998	The majority of participants had used some form of CAM in the past for their arthritis <ul style="list-style-type: none"> <li>Most commonly reported modality used for arthritis included prayer, dietary supplements and topical treatments</li> </ul>

	(e.g., WD-40, horse liniment)
Rao 1999	The majority of participants (63%) had ever used a form of CAM for their rheumatologic condition <ul style="list-style-type: none"> <li>• 56% of participants who had ever used CAM were current users; the average number of CAM participants had ever tried was 2.6 different types</li> <li>• Most commonly used CAM included chiropractic, dietary supplements, magnets and electrical stimulators</li> </ul>
Rose 2006	Most commonly used CAM were dietary supplements, aromatherapy, relaxation and spiritual healing
<b><i>Perceived benefits, motivations to use, predictors of and barriers to CAM and allied health use</i></b>	
Buchbinder 2002	Demographic characteristics associated with increased visits to CAM practitioners included female gender and no pension
Feldman 2010	26% of participants with chronic arthritis felt they required PT or OT; 96% of these participants received these services
Hughes 2009	Motivators to use acupuncture for RA were relief from RA symptoms and desire to limit medication use. Perceived benefits from acupuncture included relief of pain and inflammation, improved mobility, reduction of medication use and improvement in fatigue
Ikuyama 2009	<ul style="list-style-type: none"> <li>• Predictors of DS use were female sex, younger age and time from RA diagnosis</li> <li>• Expected effects of DS among users included relief of RA symptoms, promotion of general health and replenishing nutrients. A small proportion (2.8%) believed use of DS would cure RA</li> </ul>
Jong 2012	<ul style="list-style-type: none"> <li>• The only demographic factor significantly associated with CAM use was higher education level</li> <li>• Most commonly reported reasons for CAM use were belief in integrated disease management approach, searching for alternatives to conventional treatments and negative experiences or lack of efficacy with conventional treatments</li> </ul>
Niedermann 2010	<ul style="list-style-type: none"> <li>• Participants associated joint protection with improving pain and function, preventing disability, actively participating in their disease management and improved psychological wellbeing</li> <li>• Participants identified potential barriers to joint protection including embarrassment as well as the time and effort required to learn and implement the strategies</li> </ul>
Rao 1998	<ul style="list-style-type: none"> <li>• All participants saw their use of CAM as an adjunct to conventional treatment rather than replacing it</li> <li>• Relief of pain and symptoms was the most frequently mentioned reason for using CAM</li> <li>• Cost was only seen as an issue for participants if the CAM treatments were not perceived as effective</li> </ul>
Rao 1999	<ul style="list-style-type: none"> <li>• Most common reasons for CAM use were pain and symptom control and perceived ineffectiveness of</li> </ul>

	conventional medications
Rose 2006	<ul style="list-style-type: none"> <li>• Reasons for CAM use included perceived failure of conventional treatments (i.e., lack of efficacy, unacceptable side effects) and breakdown in confidence in medical practitioners</li> <li>• Perceived disadvantages of using CAM included financial costs and perceived reluctance of medical practitioners to refer patients for CAM</li> </ul>
<b>Miscellaneous</b>	
Van der Vaart 2014	Patients who had access to their own electronic medical records felt more involved in their treatment (44%), felt this improved the quality of their care (29%) and were less likely to undertake their own online research for health information (17%)

CAM: Complementary and alternative medicine; DT: Dietary supplements; GP: General practitioner; OT: Occupational therapy; PT: Physical therapy; RA: Rheumatoid arthritis;



**Table 3: Quality assessment of qualitative studies using CASP tool (19)**

STUDY	Domain 1	Domain 2	Domain 3	Domain 4	Domain 5	Domain 6	Domain 7	Domain 8	Domain 9	Domain 10
Ahlmen 2005	+	+	+	+	-	-	+	+	+	+
Arthur 2004	+	+	+	-	-	-	+	-	+	+
Blake 2013	+	+	+	-	+	+	+	-	+	+
Dures 2016	+	+	+	-	+	+	+	+	+	+
Flurey 2013	+	+	+	+	+	-	+	+	+	+
Fraenkel 2014	+	+	+	+	-	-	+	+	+	+
Hughes 2009	+	+	+	-	-	+	+	-	+	+
Jong 2012	+	+	+	-	-	-	-	-	+	+
Kumar 2010	+	+	+	+	+	+	+	+	+	+
Lempp 2006	+	+	+	+	+	-	+	+	+	+
Niedermann 2010	+	+	+	-	-	+	+	+	+	+
Nota 2016	+	+	+	-	+	-	+	+	+	+
Oliver 2008	+	+	+	+	-	-	+	+	+	+
Pollard 2011	+	+	+	-	-	-	+	+	+	+

Radford 2008										
Rao 1998										
Rose 2006										
Ward 2007										

**CASP quality appraisal tool**

1. Was there a clear statement of the aims of the research?
2. Is qualitative methodology appropriate?
3. Was the research design appropriate to address the aims of the research?
4. Was the recruitment strategy appropriate to the aims of the research?
5. Was the data collected in a way that addressed the research issue?
6. Has the relationship between researcher and participants been adequately considered?
7. Have ethical issues been taken into consideration?
8. Was the data analysis sufficiently rigorous?
9. Is there a clear statement of findings?
10. How valuable is the research?

= Low risk of bias

= High risk of bias


**Table 3: Quality assessment of quantitative studies using CASP tool (20)**


STUDY	Domain 1	Domain 2	Domain 3	Domain 4	Domain 5	Domain 6	Domain 7	Domain 8	Domain 9	Domain 10
Berkanovic 1995	-	-	+	-	+	+	+	+	-	+
Bhutani 2013	+	+	+	-	+	-	-	-	-	+
Buchbinder 2013	-	+	+	-	+	+	-	+	-	+
Douglas 2005	-	-	+	-	+	-	-	+	-	+
Feldman 2010	+	+	-	-	+	+	-	+	-	+
Ikuyama 2009	-	+	+	+	+	+	-	+	+	+
Jong 2012	-	-	+	-	+	-	-	+	+	+
Polluste 2012	+	+	+	-	+	+	-	+	+	+
Rao 1999	-	+	+	-	+	-	-	+	-	+
Van der Vaart 2014	-	+	-	-	+	+	+	+	-	+

**Hoy et al tool for assessing risk of bias in prevalence studies**

1. Was the study's target population a close representation of the national population in relation to relevant variables?
2. Was the sampling frame a true or close representation of the target population?

3. Was some form of random selection used to select the sample, OR was a census undertaken?
4. Was the likelihood of nonresponse bias minimal?
5. Were data collected directly from the subjects (as opposed to a proxy)?
6. Was an acceptable case definition used in the study?
7. Was the study instrument that measured the parameter of interest shown to have validity and reliability?
8. Was the same mode of data collection used for all subjects?
9. Was the length of the shortest prevalence period for the parameter of interest appropriate?
10. Were the numerator(s) and denominator(s) for the parameter of interest appropriate?

 = Low risk of bias

 = High risk of bias

1. (consumer\* or patient\* or client\* or customer\* or service user\*).tw.
2. patients/ or inpatients/ or outpatients/
3. 1 or 2
4. (rheumatolog\* or doctor\* or physician\* or practitioner\* or clinician\* or specialist\* or consultant\* or health professional\* or nurs\* or allied health or physiotherap\* or physical therap\* or chiropract\* or occupational therap\* or podiatr\* or nutrition\* or diet\* or rehabilitat\* or pain management).tw.
5. health personnel/ or allied health personnel/ or nutritionists/ or physical therapist assistants/ or physical therapists/ or exp medical staff/ or exp nurses/ or exp physicians/
6. Rheumatology/
7. Manipulation, Chiropractic/ or Chiropractic/
8. nutrition therapy/ or diet therapy/ or caloric restriction/ or diet, carbohydrate-restricted/ or diet, fat-restricted/ or diet, reducing/
9. Counseling/
10. Psychology/
11. Dietetics/
12. Podiatry/
13. Rehabilitation Nursing/
14. Nursing Care/
15. Rehabilitation/
16. Pain Management/
17. ((conservative or surgical or orthop?edic or complementary or traditional or ayurvedic or acupuncture or chinese or herbal or moxibustion or homeopath\*) adj3 (medicine\* or therap\* or treatment\* or management)).tw.
18. complementary therapies/ or acupuncture therapy/ or acupuncture analgesia/ or moxibustion/ or homeopathy/ or medicine, traditional/ or medicine, chinese traditional/
19. ((exercis\* or hyperthermia induc\* or short wave or ultra\* or ambulatory or rehab\* or self help or electr\* or manipulat\* or manual\* or heat) adj5 (therap\* or modalit\* or treatment\*)).tw.
20. physical therapy modalities/ or electric stimulation therapy/ or exercise therapy/ or hyperthermia, induced/ or short-wave therapy/ or ultrasonic therapy/
21. "Physical and Rehabilitation Medicine"/
22. (tens or transcutaneous electric nerve stimulation).tw.
23. transcutaneous electric nerve stimulation/
24. (stretch\* or strength\* or mobili\*).tw.
25. muscle stretching exercises/ or resistance training/
26. Manipulation, Orthopedic/
27. Musculoskeletal Manipulations/
28. ((joint\* or knee\* or hip\*) adj3 (replac\* or prosth\*).tw.
29. (arthroplast\* or hemiarthroplast\*).tw.
30. arthroplasty/ or arthroplasty, replacement/ or arthroplasty, replacement, hip/ or arthroplasty, replacement, knee/ or hemiarthroplasty/ or arthroscopy/
31. self-help devices/ or wheelchairs/

32. exp Dependent Ambulation/
33. canes/ or crutches/ or orthotic devices/ or braces/ or walkers/
34. (walking adj3 (cane\* or frame\* or aid\*)).tw.
35. self help devices.tw.
36. assistive devices.tw.
37. or/4-36
38. (utili\* or need\* or seek\* or retriev\* or provid\* or provision or source\* or aid\* or promot\* or access\* or demand\* or insufficien\* or deficit\* or gap\* or barrier\* or enabler\* or facilitat\* or deliver\* or implement\* or manag\* or coordinat\*).tw.
39. Needs Assessment/ or "Health Services Needs and Demand"/ or Health Services Accessibility/
40. 38 or 39
41. ((consumer\* or patient\* or client\* or customer\* or service user\*) adj4 (need\* or want\* or like\* or interest\* or prefer\* or satisf\* or perspective\* or experience\* or attitude\* or belief\* or practice\* or concern\* or support\* or participat\* or advoca\* or center\* or centr\* or orient\* or focus\* or empower\* or expect\* or opinion\* or view\* or perceive\* or perception\* or tailor\* or bespoke or involv\* or priorit\* or control\*)).tw.
42. "patient acceptance of health care"/ or patient preference/ or patient satisfaction/ or Patient-Centered Care/ or Health Knowledge, Attitudes, Practice/
43. 41 or 42
44. ((household or out of pocket) adj3 expen\*).tw.
45. "cost of illness"/ or health expenditures/ or exp "fees and charges"/
46. Waiting Lists/
47. Rural Health/ or Rural Population/
48. Urban Health/ or Urban Population/
49. Primary Health Care/
50. secondary care/ or tertiary healthcare/
51. Vulnerable Populations/
52. exp Culture/
53. communication barriers/
54. (cost\* or fee\* or charge\* or expen\* or wait\* or time\* or rural\* or remote\* or urban\* or primary or secondary or tertiary or acute\* or cultur\* or communicat\* or language\* or linguistic\*).tw.
55. 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54
56. 3 and 37 and 40 and 43 and 55
57. 42 and 56
58. exp rheumatoid arthritis/
59. (felty\* adj2 syndrome).tw.
60. (caplan\* adj2 syndrome).tw.
61. (sjogren\* adj2 syndrome).tw.
62. (sicca adj2 syndrome).tw.
63. (ankylos\* or spondyl\*).tw.
64. (psoria\* adj2 arthr\*).tw.

65. reactive arthritis.tw.
66. (reiter\* adj (disease or syndrome)).tw.
67. enthesi\*.tw.
68. inflammatory arthritis.tw.
69. ((sexua\* or chlamydia or yersinia or postyersinia or postdysenteric or salmnella or shigella or b27 or postinfectious or post infectious) adj5 arthr\*).tw.
70. (rheumat\* adj3 (arthr\* or diseas\* or condition\* or nodule\*)).tw.
71. (bechtere\* disease\* or marie-struempell disease\* or rheumatoid spondylitis or spondylarthritis ankylopoietica or ankylo\* spondyl\* or Spin\* Ankylosis or Vertebral Ankylosis).tw.
72. sacroiliitis.tw.
73. dactylit\*.tw.
74. Uveitis.tw.
75. Iritis.tw.
76. 58 or 59 or 60 or 61 or 62 or 63 or 64 or 65 or 66 or 67 or 68 or 69 or 70 or 71 or 72 or 73 or 74 or 75
77. 57 and 76

Accepted version