Patients' perceived health service needs for osteoarthritis care: A scoping systematic review

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Abstract

Objective: To identify and synthesise evidence regarding patients' perceived health service needs related to osteoarthritis (OA).

Design: A comprehensive systematic scoping review of MEDLINE, PsycINFO, EMBASE and CINAHL (1990 – 2016) was performed to capture information regarding patient perceived health service needs related to OA. Risk of bias and quality of included articles were assessed. Relevant data were extracted and collated to provide a systematic review of the existing literature.

Results: Of the 1384 identified manuscripts, 25 were relevant to areas of patient perceived need, including needs related to medical care, pharmacologic therapy, physiotherapy and exercise therapy and alternative medicine. Key findings included i) Symptom control drove the need for both conventional and complementary services. ii) An individualized relationship was sought with a practitioner knowledgeable in OA care and who adopted a holistic approach, whether providing conventional or alternative therapies. iii) Medications were required to obtain symptomatic relief, with use tempered by recognition of potential side effects and financial cost. iv) The need for allied health services was recognised, although patient and system issues were barriers to uptake. v) Patient's attitudes towards joint replacement, orthoses and physical aids were influenced by patient preferences and previous healthcare experiences.

Conclusion: This demonstrates the breadth of patient perceived needs for health services for OA, identifying their drivers, desires and perceived roles for various services. Aligning patients' perceived needs for health services with those indicated by clinical guidelines, and

enabling access within healthcare systems will be important in improving OA outcomes and optimising healthcare utilisation.

Key words: Osteoarthritis, Health Services Needs and Demand, Health services

Introduction

Osteoarthritis (OA) affects approximately 15% of the world population and is a significant cause of long-term pain and disability(1). The prevalence is projected to increase with increasing life expectancy and obesity, such that it is expected to be the fourth leading cause of disability by 2020(2). This will escalate health care costs, increasing the already significant economic burden of arthritis, which cost $128 billion USD(1.2% of the United States gross domestic product) in 2003(3).

There is no cure for OA so treatments aim at improving symptoms and function. The primary strategies recommended by all guidelines include pain and weight management strategies, and exercise interventions(4). These can be delivered by a variety of health care providers, including medical and non-medical personnel. Where conservative measures have been exhausted, and pain and disability remain significant, joint replacement may be recommended(4).

Consistent with other chronic conditions, such as diabetes, where actual clinical practice may deviate significantly from guideline recommendation(5, 6), the uptake of management guidelines for OA is low(7). Guideline implementation is a complex process, with a number of influencing factors and barriers related to guideline characteristics, social context or implementation strategies(8, 9). The implementation of guidelines by practitioners and subsequent uptake of recommendations by patients is determined by a complex interplay between health care providers, patients and resources provided within the health care system(8). Despite practitioner advice, some patients do not comply with recommendations. This may be unintentional, due to cognitive, emotional, socio-economic and practical difficulties, or intentional, due to subjective cost benefit analysis(8). One barrier to implementation is engaging appropriate active patient participation in care(10). Many patients do not engage in effective self-directed care strategies for their OA(11). This

situation is likely to be improved by better understanding patients' beliefs about health service needs for OA care in order to inform approaches aimed at maximizing participation in effective management(10, 12). Furthermore, understanding patients' beliefs is important to identify other barriers to best practice and potential strategies to create more patient-centred health services for OA care(13). Thus the aim of this systematic scoping review was to identify and synthesise the existing evidence relating to patients' perceived health service needs for OA, relevant to the current clinical environment.

Methods

We performed a comprehensive systematic scoping review of published data to identify what is known about patients' perceived health service needs related to large joint OA within a larger project examining the patient perceived needs relating to musculoskeletal health(14).

Data searches and search strategy

An electronic search of MEDLINE, PsycINFO, EMBASE and CINAHL was conducted to identify studies examining patients' perceived needs for OA health services between 1990 to June 2016. The time period (1990-2016) was chosen to include relevant studies examining the current patient perspective. The search strategy was developed by clinical researchers (Rheumatologists and Physiotherapists), a healthcare organization representing patients with OA, a patient representative and a medical librarian. It combined both MeSH terms and text words to capture the patient perspective, health service needs and OA. A systematic scoping review was performed based on framework proposed by Arksey and O'Malley(15). The term "needs" encompassed the patients' belief regarding their capacity to benefit from services, including their expectations of, satisfaction with and preference for various services(16). The detailed search strategy for MEDLINE is provided in the Supplementary Appendix.

Study screening and selection

Two investigators (MP and LE) independently assessed the titles and abstracts of all studies identified by the initial search for relevance. Manuscripts were included if they met the following criteria: publications in English, adults, concerning the patient perspective of need, in relation to health services associated with OA and full text articles. Study populations with arthritis, including OA, that did not report OA results separately, and work presented only in abstract form was not included. There were no criteria regarding study design. Studies that appeared to meet inclusion criteria were retrieved and assessed for relevance. A search of the reference lists of relevant studies for inclusion was conducted. Any disagreements were resolved through consensus or in conjunction with the senior author (AW)

Data extraction and analysis

Two investigators (MP and LE) independently extracted the data from studies using a standardised data extraction form. The following data were extracted: (1) author and year of publication, (2) study population (3) primary study aim and (4) study methods. Included studies were reviewed by two authors independently to identify aspects of health services for OA that patients had a preference for, expected, or were satisfied with using principles of meta-ethnography to synthesise qualitative data(17). In the first stage, one author (LE) developed a framework of concepts and themes, based on study data and pertinent discussion points. In the second stage, another author (MP) independently reviewed the studies and further developed this framework. In the third stage two authors (FC and AW) with over 15 years of rheumatology consultant-level experience independently reviewed the concepts and themes to ensure clinical meaningfulness and face validity.

Assessment of bias and methodological quality

To assess the methodological quality of the studies, two reviewers (MP and LC) independently assessed all of the included studies. For qualitative studies, the Critical Appraisal Skills Programme (CASP) score criteria(18) was employed. Hoy et al's risk of bias tool(19) was utilized to assess the internal and external validity of quantitative studies. Low risk of bias of quantitative studies was defined as scoring 8 or more "yes" answers, moderate risk was 6 to 7 "yes" answers and high risk was 5 or fewer "yes" answers. Discrepancies were resolved by consensus. Disagreements in scoring were reviewed by a third reviewer(AW).

Results

Study characteristics

Of the 1384 manuscripts identified by the search, 25 articles met inclusion criteria (20-43). A PRISMA flow diagram demonstrates the selection of papers(Figure 1).

Table 1 provides the descriptive characteristics of included papers. 12 (50%) of studies were from North America or Australia(20, 21, 26, 28-30, 32-35, 37, 39), 11 (44%)of studies were from Europe, including United Kingdom (UK) (22-24, 27, 36, 38, 40-44) and 2 (8%) were from South-East Asia(25, 31). Most participants were recruited from general practice or outpatient clinics(20, 22, 25, 27-29, 31, 33, 35, 36, 39-41). Other studies recruited patients from disease registries(30), medical records(21, 42), pharmacy customers(23), surgical waiting lists(34, 38), other studies on OA(44), and the community (26, 43).

Most studies involved only those with OA(20-26, 29-33, 35-44). Three studies included a population with inflammatory arthritis(27, 28, 34). Data relating to OA was separated from other conditions in these manuscripts.

Nine studies used quantitative methods, including written questionnaires(20, 27, 33, 37), computer questionnaires(29, 30) or interviews(28, 32, 34). Twelve studies used qualitative methods including focus groups(23, 26, 35, 36, 39) and individual interviews(21, 22, 24, 25, 31, 38, 40, 42-44). One study employed both quantitative and qualitative methods with interviews, patient diaries and group teaching sessions(41).

Risk of bias

The risk of bias was assessed in all included studies (Tables 2 and 3). Most studies had high risk of bias, due to insufficient representation of the national population and inadequate case definition and recruitment strategies. The prevalence period for OA was not defined in most qualitative studies.

Areas of need identified

The perceived health service needs of patients with OA were categorized into 7 areas of need (Table 4).

1. Patient perceived needs related to medical care

Patients identified the need for medical care when the frequency and intensity of symptoms increased(40) or when their ability to perform daily activities was affected(24, 25). Patients sought care from their general practitioner (GP) to obtain a diagnosis and explanation for

their pain(24, 44). Some patients were reluctant to seek medical care due to the perception that their symptoms were associated with normal aging (43). Perceived medical competence conveyed a sense of security to patients and was related to physicians' age, reputation and training(21). Confidence in the practitioner influenced the patient-physician relationship and this depended on the perception of receiving individualised care(21, 44), which related to the interpersonal skills of the physician and ability to adopt a holistic approach to care(21). Patients identified a number of factors associated with dissatisfaction with the provider, including insufficient practitioner knowledge(21, 23, 24, 40), an emphasis on analgesic therapies only(21, 26, 40), rejection of complementary and alternative medicine (CAM)(21) and failure to acknowledge pain during the examination (26). Patients also identified poor practitioner communication skills to be a source of dissatisfaction (23, 26) and attributed their lack of knowledge about their medical diagnosis to this(26). Patients felt uncomfortable speaking about medications during consultations due to time pressures(35, 42) and preferred requesting drug information from pharmacists or practice nurses (42) because they listened to patients' concerns(35).

2. Patients' perceived needs of pharmacologic therapy and pain management

Patients prioritized improvements in pain management, mobility and function(41). Desirable pain management included eliminating ambulatory pain and reducing difficulty performing daily activities(24, 30). Patients' opinions on treatment differed depending on whether they experienced occasional or chronic pain from knee OA(21). Symptomatic relief was the expectation of patients with sporadic knee pain(21), however, patients with chronic knee pain desired disease-modifying treatment. Some patients considered dietary supplements as natural alternatives to pharmacologic medications. Due to this, they were more desirable(21).

The ease of using drugs compared to the effort required to participate in non-pharmacologic treatments meant that patients preferred to use medications to manage OA(35). They also desired a single medication instead of multiple to treat OA(39) and a therapy that provided permanent benefit(26). Patients identified the effectiveness of pain control as of most importance, followed by risk, cost and administration route(29). However, another study found that treatment efficacy did not influence patient medication choices, as this was primarily driven by fear of side effects(33). Acceptable risk was dependent on the baseline level of ambulatory pain and the type of symptom relief(30).

Medications were considered as both therapeutic and noxious by patients(21, 24). Some patients would only take medications if pain was intolerable(42). Topical treatments were considered positively by patients who could self-administrate with concurrent massage(21). Oral preparations were useful to relieve symptoms periodically but were not considered a long-term solution(21). Medication side effects, in particular cardiovascular effects, were patients' primary concern(21, 24, 30, 31, 33). Pharmacological effect on the liver, kidney and stomach were also considered significant(31, 33). Patients viewed opiates to be associated with severe illness, and therefore often rejected this(42). The rapidity of action of corticosteroid injections was emphasized however cartilage weakening was a concern(21). Hyaluronic acid injection was perceived to be a less aggressive procedure and viewed positively in one study(21), but perceived to be damaging to cartilage in another(31). Contrasting opinions on medications in studies may be attributed to different population characteristics.

Medication cost impacted patients' choice to continue the medication(33, 35). Some patients prioritised chronic conditions, such as diabetes, over OA and thus they omitted analgesics

239 unless their OA pain was severe(35). Other concerns with pharmacological therapy included
240 medication schedule complexity(33, 35).
241
242 *3. Patient perceived needs related to physiotherapy and exercise therapy*
243
244 Patients sought physiotherapists for knee OA(25) and wanted to achieve better health through
245 exercise participation and weight loss(41). Patients believed this was important for pain relief
246 and to increase muscle strength(21, 25). Also, patients gained knowledge regarding self-
247 management of joint pain and insight into how others coped with their pain through exercise
248 classes(23). However, for patients who identified a need for rehabilitation, most did not
249 receive this service(28).
250
251 Patient disinterest and low motivation were common barrier to participation in exercise
252 therapy(20, 42). Others included physical limitations, pain (20, 42), transport difficulties(20),
253 work and family commitments(20), course scheduling(20), and venue preference(20). An
254 exercise program that did not account for multisite pain also reduced participation(23). Some
255 patients with knee OA needed to adjust exercise to manage their pain(25). Most patients
256 preferred to attend an exercise session during the day, with few favouring the evening or
257 weekend(20). Some patients did not attend physiotherapy regularly as they had other methods
258 of staying active(24).
259
260 *4. Patient perceived needs related to complementary and alternative medicine (CAM)*
261
262 90% of patients with OA regularly used CAM or had done so in the past(39). Desire for pain
263 relief was the main reason for seeking CAM(24, 39), as well as to reduce conventional

medicine intake and to delay time to surgery(21). In a study examining acupuncture, patients enjoyed the supportive and shared experience of the group environment(22). Factors contributing to patient satisfaction with CAM included ease of access, good communication skills and empathy of CAM practitioners and the holistic approach to patient care(21, 22). Patients also preferred flexibility in the appointment system and sufficient space and staffing when seeking non conventional physical therapies(22, 25). The main barrier to using CAM was its cost(25).

5. Patient perceived needs related to joint replacement surgery

Some patients believed joint replacement surgery to be the only effective treatment option for OA(36), with excellent outcomes(24). Others considered surgery only when pain significantly affected their ability to perform daily activities(24). Patient's willingness to undergo joint replacement surgery was associated with a preference for an experienced surgeon, a good understanding of the procedure, perceiving less pain and functional limitation after surgery and knowing someone who joint replacement surgery(24, 32, 37). McHugh reported a patient wanting to withhold information about his concurrent medical conditions in order to proceed with surgery(38). In contrast, some patients wanted delay joint replacement(21) due to fears of anaesthesia, nosocomial infections and poor surgical outcomes(21, 43). Access to surgery was a concern, in addition to inconsistency between different clinicians' advice regarding surgery(36, 44).

6. Patient perceived needs related to access to health services

Numerous factors influenced patient accessibility to health services, including financial constraints and lack of transportation(25-27, 34, 36). Weekday, morning appointments were preferred by patients(27), however, 75% of patients from a study conducted in the UK preferred to attend the closest hospital rather than their local primary care centre(27). Patients desired easy access to specialist knowledge(36) and believed that GP's were too busy to discuss OA and were not specialists in arthritis(36, 42). There was no association found between maximal acceptable waiting time and OA symptomatic burden(34). Treatment cost was a significant factor affecting therapy choice(25) and lack of care continuity was a patient concern(26, 43).

7. Patient perceived needs related to orthoses and physical aids

To relieve knee discomfort, patients perceived a need for auxiliary devices including braces and gait aids(25, 31). Patients appreciated the increased feeling of stability with knee orthoses but had aesthetic concerns(21). Patients with foot OA preferred fashionable footwear(40). Insoles were considered favourably and considered a viable option to improve load distribution in the affected limb(21). Patients considered gait aids and wheelchairs as transient options, as they implied old age and loss of autonomy(21). Patients had little awareness of living aids or home adaptations that were available through social services(38).

Discussion

This review identified a number of areas of perceived need related to health services for OA. The decision to access medical care was driven by pain and physical functional limitations. Patients valued tailored management plans from a practitioner who was knowledgeable and

delivered holistic care. Patients expected medications to provide symptomatic relief, but were concerned about side effects. Pain severity and out of pocket costs affected medication choice. Patients saw a role for exercise therapy in OA management, however access and cost presented barriers to uptake. The desire for CAM was common amongst OA patients, primarily driven by the desire for pain relief. Patients' attitudes towards joint replacement were divided and orthoses and physical aids were viewed as transient management options.

Patients primarily sought medical care when symptoms intensified and interfered with their life(25, 40), in order to reduce pain and improve quality of life(23, 36)**.** They wanted their doctor to acknowledge the symptom severity(21) and to provide empathy, hope, reassurance, specialist knowledge and education about OA in a personalized way(21, 45). As effective management of OA requires active patient participation, particularly in performing exercise and weight loss(13), delivery of patient centred care is critical(21). Aligning practitioner practice behaviours to the advocated NICE (National Institute for Health and Care Excellence) OA guidelines, which advocate a holistic approach to the management of OA, centred on access to appropriate information, is essential for the delivery of effective management(46, 47). Education provided by the practitioner has been shown to improve quality of life among patients with arthritis(48), probably by increasing their acceptability and compliance(21), subsequently improving OA outcomes.

Medications are commonly used in OA, perhaps in part because they are a passive treatment, requiring less effort to reduce pain than physical treatments. This review found that patients expected medications to be effective but were concerned about side effects. Patients reported titrating prescribed medications to their level of pain and functional impairments(35). The extent to which this reflects reality is unclear as evidenced by the increasing uptake of

prescription opiates use for chronic pain associated with musculoskeletal conditions(49). There was some evidence that in the setting of severe OA pain, patients were willing to accept higher medication risks for improvements in pain(29, 30) and to prevent progression of OA(29). Despite non-pharmacological therapies such as exercise programs being recommended in clinical guidelines and acknowledged by patients as effective(21), barriers to their use were readily presented. These include inconvenient appointment times, patient disinterest, low motivation, physical limitation and financial cost(20)**.** However, it may also reflect the appeal of ease of medication use compared to participation in active therapies(35). Unawareness of the efficacy of non-pharmacological therapy for OA may also present as barriers to participation.

Patients' use of CAM is known to be common(39). Among those with chronic disease, people with arthritis were most likely to report ever using CAM(39). This review found that patients' perceived need for CAM was driven by similar reasons as for conventional medications, primarily in search of pain relief(39). Patients considered supplemental CAM could reduce conventional medicine intake and delay time to surgery(21). The preference for CAM may be a result of the lack of effectiveness in conventional analgesia for OA, with 54% of patients experiencing inadequate pain relief(50). Increasing CAM use may also be attributed to the perception that alternative care providers deliver better legitimization of the person's condition, are more empathic, have more time, are more holistic and incorporate the patients' condition into lifestyle recommendations(21). Patients perceive CAM practitioners as engendering a better therapeutic relationship, providing more hope than the impression of nihilism received from conventional health practitioners(51). This suggests a gap in conventional health education provision and highlights that patients have substantial unmet needs for information and support(35). Despite high expectations of CAM, patients with lower back pain appeared to recognise that these therapies have limited efficacy(52).

However, despite limited evidence for the efficacy of CAM in OA, there is widespread use(39), with the potential for medication interactions and side effects. Practitioners need to actively enquire as to whether their patients are taking alternative therapies to inform them of these risks(53).

Physical therapy, a cornerstone of the management of OA, is perceived to be important by patients. Thus patient beliefs are aligned with guideline recommendations for OA management(54-56): despite this, uptake is poor. There are system barriers, including lack of service provision, inconvenient appointment times and venue location(20)**.** Patient factors, including disinterest, physical limitation and patient cost also play significant roles(20). Considering that active participation by patients is essential for effective management of OA, supporting patients to engage in self-management by using an approach that considers health literacy and behaviour change support, is important. The patient's own care experience is also a crucial component of the therapeutic approach(23) and guideline recommendations need to be acceptable to patients for adherence to have clinical impact(57). Health coaching for professionals, in particular in motivational interviewing, behaviour change methods and integrated chronic care programs may be of assistance in overcoming the identified patient factors(58, 59)**.** The implementation of guidelines is also limited by health service availability. Thus, developing accessible, economically feasible methods to deliver physical therapy, that is acceptable to patients may improve physical and exercise therapy uptake, thus optimizing outcomes for both the patient and health care system. In this regard, telehealth and other digital-enablers are likely to become increasingly adopted(60).

Weight loss is a core component in the management of OA, being associated pain reduction and the only proven intervention to reduce disease progression(13). Despite this, no studies identified the patient perceived need for weight loss services. It has been shown that patients

with OA are aware of the need for weight loss(61) and desire information regarding lifestyle modification that may improve their OA symptoms(42), however, they make few effective efforts to lose weight(11, 61)**.** This need was not captured by this review. It is possible that no study has provided a platform for this need to be expressed. Alternatively, both health care professionals and patients are pessimistic about the likelihood of successful weight loss, and thus do not attempt this approach. This management issue needs to be raised so that the opportunity of the teachable moment may arise, and facilitate behaviour change with view to improving outcomes in OA(13).

This review identified contrasting opinions regarding joint replacement surgery. Factors including patient beliefs, expectations of surgery, surgical experiences of other people and coping mechanisms have an impact on joint replacement utilization(32, 37, 62). Patient race has been shown to result in variations in the utilization of joint replacement surgery(32, 63) and disparities in surgical advice and service access for OA also contribute to conflicting patient views and concerns(36, 38). Discussion regarding patient attitudes to joint replacement needs to consider these conflicting influences on patient preference for this therapy.

This review was limited as few studies specifically examined patients' perspective of OA health service needs since 1990. The identified studies had a variety of primary aims, design and patient populations. Most of the results were obtained from studies that did not directly address the review question. Thus the forum for some needs to have been articulated may not exist; therefore a lack of evidence must not be taken to indicate a lack of need. For example, although anecdotally, many people use chiropractors for OA and dieticians for weight loss, studies examining the patient's perceived need for these services were not found. Elements of

patient access to numerous health services was also not explored, including patient perception on waiting times for physician review. Patient perceived needs for healthy lifestyle services were not identified in this review, although the related health services were included in the search strategy. These are important gaps in the literature for future research that need to be addressed to reduce the burden of OA. Many studies were at risk of selection bias. There is the potential for lack of generalizability to patients who are not from North America, Western Europe or Australia, since most data came from those countries. The perception of need for services is likely to vary considerably in different countries with diverse social systems, as are the services available. Most of the included studies were based in primary care. Also, the average age of participants in most of the studies was above 50, with a female predominance. Whilst this is consistent with the demographics of patients with OA, they maybe less generalizable to other sub groups.

This review has several strengths. A comprehensive search of several databases was performed. Two reviewers independently reviewed the search output, extracted data, classified interventions, and assessed for bias. The results from the identified studies tended to be consistent, with few conflicting results.

Despite the evidence for ~~active therapies~~therapies that require active patient participation for OA, adherence is low. This review has shown that this may be because current therapies do not meet patient's expectations for holistic personalised care and adequate pain control. As the patient's perception of need drives their use of health services, they turn to other modalities of care, such as CAM. A better understanding of patient OA needs has the potential to reduce barriers to the uptake of evidence based care, guide the provision of

patient-relevant services, thus optimizing patient outcomes and healthcare system utilisation(Figure 2).

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Anita Wluka (anita.wluka@monash.edu) and Michelle C Papandony (michellecp89@gmail.com) take responsibility for the integrity of the work as a whole.

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Competing interests

Not applicable

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Figures

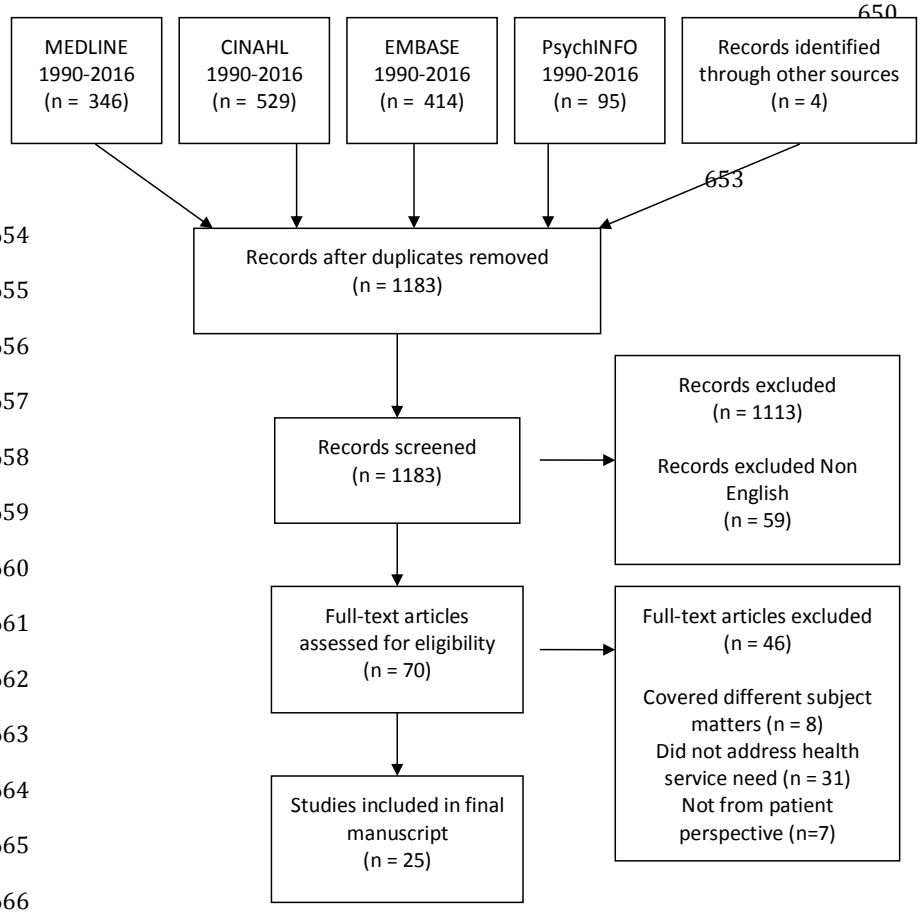

Figure 1: PRISMA flow chart for study selection

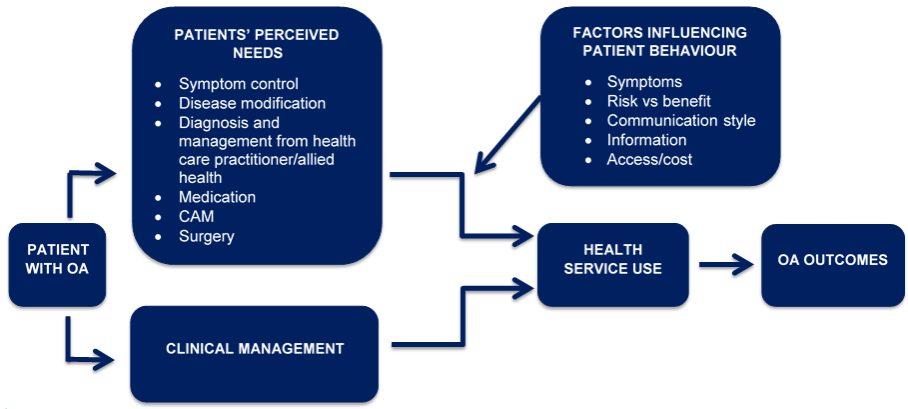

Figure 2: Diagram representing the drivers for patient health service utilisation in OA~~Diagram representing the interplay between the patient and health service utilisation~~

This diagram illustrates the various factors associated with patients' use of health services. These factors include both patient perceived needs and the clinical management recommended by health care providers, whether medical, non-medical or allied health. Health service uptake is influenced by patients' behaviour, which is determined by symptoms, patient perceived risk versus benefit, patients' perception of the health care providers' communication style, information received from other sources, cost and accessibility of management options.

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Table 1: Characteristics of included manuscripts

Author and year	Diagnosis of osteoarthritis	Number of participants	Source of participants	Age & gender	Aim	Study design
Ackerman (20) 2013 Australia	Diagnosis of hip or knee OA from radiology reports or able to be classified according to ACR criteria classified according to ACR criteria	126 Hip OA -39 Knee OA - 79 Hip and knee OA -8	Patients with hip or knee OA referred to orthopaedic surgeons or rheumatologists at 6 public and private hospitals in Victoria	76 female (60%) Median age – 67 Range 57-73	To improve understanding of barriers to participation in community based arthritis self management programs and patient preferences for self-management education	Quantitative Written questionnaire

Alami (21) 2011 Canada	Not specified	81	Patients with knee OA selected from files of care providers not involved in the interview process	59 female (73%) Range 45 ->80 years	To identify the views of patients and care providers regarding the management of knee osteoarthritis and to reveal potential obstacles to improving health care strategies	Qualitative Semi-structured interviews

Asprey (22) 2012 UK	Not specified	16	Patients of acupuncture clinics who were provided information packs and responded	Female 10 (63%) Aged 48-89	To investigate the acceptability and perceived advantages and disadvantages of acupuncture delivered in the group setting for the treatment of OA	Qualitative Semi structured interviews then sequential interviewing after acupuncture therapy.

Baumann (23) 2007 France	Not specified	96	Customers of 10 pharmacies in 10 towns in 10 regions randomly selected from 22 French regions. The first 10 customers who came to purchase any medication.	Female 78 (81%) Mean age 65 Range 42-89	To evaluate the expectations of OA patients in France and to consider how the information gathered may be used to improve the heath care provision and patient-doctor relationship they received.	Qualitative Focus groups

Brembo (24) 2016 Norway	Not specified	13	Purposive sample of patients with hip OA recruited from a GP practice and from the orthopaedic outpatient clinic at the local hospital	Age range 60-89 54% female	To investigate patients' need for information and their personal emotional needs.	Qualitative Interviews

Chan (25) 2011 Hong Kong	American College of Rheumatology diagnostic criteria for knee OA.	20	Convenience sampling in a private general practice clinic	Female 13 (65%) Mean age 57	To evaluate the influence of different pain patterns on the quality of life of patients with knee OA and to investigate their interpretation and coping strategies for the disease using patient interviews.	Qualitative Semi structured interviews

Davis (26) 2002 USA	Self reported OA.	57	Sample of patients from retirement settings or their own home. Recruitment via printed flyers.	Female 45 (79%) Mean age 79.3 Age range 66 – 95	To explore barriers to pain management experienced by older adults with arthritis, identify themes, and develop a theoretical model of relationships among the thems.	Qualitative Focus groups
Douglas (27) 2005 UK	Not specified	34/419 8% degenerative joint disease -	All patients attending Rheumatology Outpatients at Dudley Group of Hospitals NHS Trust over a 2-week period were invited to participate	Female 302 Age range 16-92, 38% > 65 years	To determine the preferences of rheumatology patients for the time and location of their outpatient appointments	Quantitative Questionnaire

Feldman (28) 2010 Canada	Physician confirmed chronic arthritis. Included both RA and OA Type of joint not specified	211	Primary care settings in Quebec (family medicine groups, community clinics, solo practitioners', walk in clinics, hospital based family medicine units.	Female 152 (72%) Mean age 68.3	To examine issues related to access to physical and occupational therapy services for patients with chronic arthritis	Quantitative Interview
Fraenkel (29) 2014 USA	Self reported knee pain or physician diagnosed knee OA	304	Patients attending general medicine and subspecialty outpatient clinics affiliated with a university medical centre.	Female 210 (55%) Median age 57 Age range 34-89	To use patient preferences to inform the development of disease modifying drugs for osteoarthritis	Quantitative Computerized questionnaire

Hauber (30) 2013 USA	Self reported doctor diagnosed OA Type of joint not specified	289	Invited participants mail invitation from Harris Interactive online chronic illness panel in the UK. Panellists are screened for OA.	Female 188 (65%) Mean age 59	To assess patient preferences for treatment-related benefits and risks associated with the use of NSAIDS in the management of OA	Quantitative Computerized questionnaire Discrete-choice experiments
Kao (31) 2014 Taiwan	Radiographic evidence of OA	17	Patients at orthopaedic clinics of two medical centres	Female 14 (82%) Mean age 49.6	To understand the illness experiences of middle aged adults with early knee OA	Qualitative Semi structured interviews

Kwoh (32) 2015 USA	Moderate to severe OA based on WOMAC and radiographic evidence of OA and clinical diagnosis of OA based on ACR guidelines	799	Participants recruited from University of Pittsburgh and the Veterans Affairs Pittsburgh Healthcare Systems clinics, local advertisements and mailings.	White participants mean age 64.5 (SD9), 59% female African-American participants mean age 58.7 (SD8), 73% female	To identify the determinants of knee osteoarthritis patients' preferences regarding total knee replacement by race and to identify the variables that may mediate racial differences in willingness to undergo total knee replacement	Quantitative Interviews

Laba, T.L (33) 2013 Australia	Radiological confirmed OA in a symptomatic knee.	188	Participants completing Long-term Evaluation of Glucosamine Sulphate study. Recruitment by small advertisements in local and national newspapers or directly from general practice.	Female 104 (55%) Mean age 62	To estimate the relative influence of medication related factors and respondent characteristics on decisions to continue medications among people with symptomatic OA	Quantitative Paper survey

Llewellyn-Thomas (34) 1998 Canada	Not specified	124 86 – OA	Patients on waiting lists for joint replacement surgery by one of 19 orthopaedic surgeons in 8 cities in Ontario.	Male 48 Female 76 Mean age unclear	To determine patients' attitudes towards time waiting for hip or knee replacement. Patients considered a hypothetical choice between a 1month wait for a surgeon who could provide a 2% risk of post operative mortality, or a 6 month wait for joint replacement with a 1% risk of post operative mortality.	Quantitative Questionnaire

Maly (44) 2006 UK	Physician and radiographic OA	3	Patients enrolled in OA study	Female 2 (66%) Age range 62-87 years	To understand the experience of living with knee OA in older individuals	Qualitative Interviews
Manias (35) 2007 Australia	Self reported OA	34	From an ambulatory care clinic of a metropolitan teaching hospital and an arthritis consumer organization in Australia.	Female 27 (79%) Mean age female 67 Mean age male 75	To investigate perceptions of and experiences with managing drug regimens from the perspectives of consumers with OA and coexisting chronic conditions and of healthcare professionals from diverse backgrounds.	Qualitative Focus groups

Mann (36) 2011 UK	Not specified	16	Patients with hip or knee OA or inflammatory arthritis were selected from the practice database of a large general practice	Female 9 (56%) Mean age 68	To explore the opinions of patients and health professionals about the provision of health care for people with osteoarthritis and possible service improvements	Qualitative Focus groups
McHugh (38) 2007 UK	Clinical diagnosis (Waiting list for joint replacement)	21	Patients on the waiting list for hip or knee joint replacement at a regional orthopaedic centre (UK)	Female 16 (76%) Mean age 65	To explore within primary care the experiences of management and care of individuals with end stage lower limb OA who are on the waiting list for a joint replacement	Qualitative Semi structured interview

O'Hara (37) 2015 USA	Not specified	62	Recruited patients with end-stage shoulder OA awaiting total shoulder arthroscopy from a single surgeon's practice	Mean age 70.9 (SD 9.6) 53% female	To determine patient preferences related to accessing total shoulder arthroplasty, specifically comparing out-of-pocket payments for treatment, travel time to hospital, the surgeon's level of experience and wait times.	Quantitative Questionnaire

Rao (39) 1998 USA	Clinical diagnosis	33 10 - OA	Patients with RA and OA from 3 outpatient sites associated with Indiana university medical centre.	All white male Average age 51	To understand arthritis patients' use of unconventional therapies	Qualitative Focus groups – 3 with RA patients and 1 with OA patients
Rosemann(42) 2006 Germany	ICD coding for OA from GP computer files.	20	Patients with OA from GP practices.	Female 12 (60%) Mean age 56 Age range 40 - 78	To identify health care needs of patients with OA and to reveal possible obstacles for improvements in primary care management of OA patients	Qualitative Semi-structured interviews

Sanders (43) 2004 UK	Clinician diagnosed osteoarthritis or arthritis.	27	Sampling from data from two questionnaire surveys.	Female 17 (63%) Median age 76 Age range 51 - 91	To explore the barriers to health-care utilization in respondents with moderate to severe hip/ knee symptoms of pain and disability	Qualitative Interviews
Thomas (40) 2013 UK	Radiological confirmed symptomatic foot OA	11	Three GP's (North Staffordshire)	Female 6 (55%) Age 56-80	To examine the experiences of primary care consultation among older adults with symptomatic foot osteoarthritis	Qualitative Semi-structured interviews

Victor (41) 2004 UK	Radiologically confirmed knee OA	170	Twenty-two general practices referring patients to the Rheumatology Department at St George's Hospital. (South-west London)	Female 124 Male 46 Mean age 63	To explore the patients' perspective on the meaning and significance of living with arthritis, identified through qualitative and quantitative approaches undertaken during a trial that evaluated the effectiveness of a primary care-based patient education program.	Qualitative and Quantitative Interview Patient diaries Group teaching session

Table 2: Quality assessment of quantitative studies (19)

STUDY	Criteria 1	Criteria 2	Criteria 3	Criteria 4	Criteria 5	Criteria 6	Criteria 7	Criteria 8	Criteria 9	Criteria 10	Total
Ackerman (20)	+	+	+	-	+	+	-	+	-	-	14
Douglas (27)	-	-	-	-	+	-	-	+	-	-	18
Feldman (28)	-	-	-	-	+	-	+	+	-	-	17
Fraenkel (29)	-	-	-	-	+	-	-	+	-	-	18
Hauber (30)	-	-	-	-	+	-	+	+	-	-	17
Kwoh (32)	+	+	-	-	+	+	-	+	+	-	14
O'Hara (37)	-	-	-	-	+	-	-	+	+	-	17
Laba (33)	-	-	+	-	+	-	-	+	-	-	17
Llewellyn-Thomas (34)	-	-	-	+	+	-	+	+	-	-	16
Victor (41)	-	-	-	-	+	+	-	+	-	-	17

Legend:

Yes: + symbol No: - symbol

Criteria:

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?

Table 3: Quality assessment of qualitative studies (18)

STUDY	CASP 1	CASP 2	CASP 3	CASP 4	CASP 5	CASP 6	CASP 7	CASP 8	CASP 9	CASP 10
Alami (21)	+	+	+	+	-	?	+	?	+	-
Asprey (22)	+	+	+	-	+	?	+	+	-	-
Baumann (23)	+	+	+	-	-	-	?	-	+	+
Brembo (24)	+	+	+	-	-	+	+	+	+	+
Chan (25)	+	+	+	-	+	+	-	+	+	+
Davis (26)	+	+	+	+	-	+	+	+	-	+
Kao (31)	+	+	+	-	+	?	+	+	+	+
Maly (44)	+	+	+	-	-	+	+	-	+	+

Manias (35)	+	+	+	-	-	+	+	?	+	+
Mann (36)	+	+	+	-	-	-	+	+	+	+
McHugh (38)	+	+	+	+	+	-	+	?	+	+
Rao (39)	+	+	+	-	-	+	+	+	+	+
Rosemann (42)	+	+	+	+	-	-	+	-	-	+
Sanders (43)	+	+	+	+	+	-	+	-	+	+
Thomas (40)	+	+	+	+	-	-	+	?	-	+
Victor (41)	+	+	-	-	-	?	?	?	-	-

Legend:

Yes: + symbol, No: – symbol, Can’t tell: ? symbol

CASP Criteria:

1. Was there a clear statement of the aims of the research?
2. Is a 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?

Table 4: Areas of patient perceived health services needs related to osteoarthritis

Author (Year)	Results
Patient perceived needs related to medical care	
Patient reasons for seeking medical care	
Brembo (24) 2016 Norway	• To get an explanation of what was causing pain and interfering with their daily functioning in order to control pain and improve function
Chan (25) 2011 Hong Kong	• Patients sought primary care providers and orthopaedic specialists when their social lives or daily activities were affected
Maly (44)	• Patients accessed their family doctor to help manage their OA

Sanders (43) 2004 UK	• Patients perceived their symptoms as being associated with normal aging. They were pessimistic about formal medical care, making them reluctant to seek care. • Some patients, working full time, indicated a need for OA treatment.
Thomas (40) 2013 UK	• Patients saw their GP for increasing frequency and intensity of symptoms.
Patient perceived needs of the outcome of medical care	

Alami (21) 2011 Canada	• Medical competence was reported and assessed by physicians' perceived reputation, age and training. All these factors conveyed a sense of security to the patients • Confidence with the practitioner seemed to determine the doctor-patient relationship and depend on a combination of factors. • Patients liked the feeling of being in a specific and individualised relationship with care provider. This feeling was related to the interpersonal and communication skills of the physicians and ability to adopt a holistic patient approach • The main source of dissatisfaction was the practitioner accentuating the patients feeling of uncertainty about OA. This occurred when the practitioner gave unclear explanations and had insufficient knowledge • Patients complained about not being recognised and practitioners trivializing OA • Patients disliked when physicians imparted the feeling that therapeutic options were only palliative. This led patients to question the efficacy of modern medicine • Practitioner rejection of alternative medicine options was a source of patient dissatisfaction

Baumann (23) 2007 France	• Patients felt they had too little opportunity to express themselves to the practitioner • Patients reported a need for more clarity, accessibility and simplicity • Patients reported lack of communication skills from practitioners • Practitioners were poorly informed of OA condition • Computers formed barrier to communication • Patients did not see much of a practitioner interest in OA diagnosis
Brembo (24) 2016 Norway	• Patients sought care from their GP to get an explanation for their pain • Patients identified available time with the clinician as a barrier
Davis (26) 2002 USA	• Patients sought good communication with health care providers, particularly regarding medications. • Patients attributed their lack of knowledge about their medical diagnosis and treatments to poor communication with their health care provider. • Failure of providers to suggest management techniques other than medicine was associated with patient dissatisfaction. • Participants sought acknowledgement pain during examination by the health care provider.

Maly (44)	• Patients desired medical expertise and personalised therapy from the practitioner • Patients lost trust in their doctor if there was discrepancy between their own experience and the doctors assessment
Manias (35) 2007 AUS	• Patients felt relatively uncomfortable speaking about medications during medical consultations because of lack of time to discuss issues with physicians and feelings of embarrassment about asking for information. • On the other hand, patients felt comfortable requesting drug information from pharmacists because they perceived that pharmacists were readily available and listened to patients' concerns. • Patients emphasized the pharmacist's role in helping them understand drug use and adverse effects. The patients believed that, compared with other healthcare professionals, pharmacists were best able to support them in taking medications to suit specific needs, and perceived to be the central educator about managing medications.
Rosemann (42) 2006 Germany	• Patients wanted more GP time. They felt that their GP lacked time. • Patients wanted GPs to more openly address psychological complaints and ask direct questions about mood. • Patients identified roles for practice nurses to include informing patients about non pharmacological approaches to manage their OA, and to ask about medication side effects and mood.

Sanders (43) 2004 UK	• Patients identified that GP's could not help patients with their pain and therefore they did not raise the issue in the consultation.
Thomas (40) 2013 UK	• Patients perceived that they were given little information and brief assessment/ not taken seriously by the GP • Majority described negative consultation experiences • Emphasis on symptom management with analgesics was unwelcome: desire for the provision of sound advice, other than that on medication use
Patient perceived needs of pharmacologic therapy and pain management	
Patient perceived need of outcomes from taking medication	

Alami (21) 2011 Canada	• Patients' views of treatments differ depending on whether knee OA is considered an occasional or chronic problem • Expectations of those with sporadic knee pain – symptom relief • Expectations of those with chronic knee pain – disease modifying treatment or stop OA evolution • Pharmacological treatments are considered useful for symptoms (immediate pain relief) but unsuccessful for disease evolution • Oral medications: periodic symptomatic helpers. Considered occasional. • Local topical treatment is associated with the idea of pain relief are considered positively. • Corticosteroid injection: efficacy and rapidity of action are emphasized.
Davis (26) 2002 USA	• Patients wanted therapy to provide a more permanent benefit.

Fraenkel (29) 2014 USA	• Almost 60% of patients are willing to accept substantial risk in order to prevent progression of OA.
Hauber (30) 2013 USA	• Patients ranked both eliminating ambulatory pain and difficulty doing daily activities as the most important benefit outcomes (6.32; 95% CI: 5.0-7.6), followed by eliminating severe resting pain (2.80; 95% CI: 1.8-3.8) and eliminating severe stiffness (2.65; 95% CI: 0.9-4.4) – overall therapy (not medication specifically)
Manias (35) 2007 AUS	• Most patients perceived that chronic conditions such as diabetes, hypertension and IHD had a greater impact on their overall health than did OA. Therefore, they endeavoured to take all drugs required for those other conditions
Rao (39) 1998 USA	• Patients wished that a single medicine instead of multiple medications could be used to treat their arthritis

Rosemann (42) 2006 Germany	• Patients wanted their pain to be alleviated, however, rejected drugs without explanation. • Patients wait until they can take the pain no longer.
Victor (41) 2004 UK	• Pain management and improvements in mobility/ functional ability were the areas of health where respondents prioritised improvements
Patient perception of risks and benefits related to the decision to take pharmacologic therapy	

Alami (21) 2011 Canada	• Drugs considered as both therapeutic and noxious by patients. General attitude designated as “the less drug therapy possible” • Patients concerned about fear of side effects and dependency of oral medications, especially opiates • Local topical treatment is associated with the idea of pain relief are considered positively. Numerous reasons for being considered positively including self administration and massage • Corticosteroid injection efficacy and rapidity of action were emphasized, but patients worried about the component injected and potentially weakening the cartilage • Hyaluronic acid injection was viewed with a positive image because it is thought to be a less aggressive procedure than corticosteroid injection • Dietary supplements are considered natural alternatives to pharmacological drugs and as such are desirable. • The absence of side effects or contraindications to dietary supplements was emphasized.

Brembo (24) 2016 Norway	• Most patients had clear objections about taking analgesic medications daily, and were concerned with possible side-effects • One participant stated that they were concerned the medications might worsen their hip OA • Despite the general non-adherence to analgesics among participants, some felt that regular pain medications helped them cope with the pain • Some patients take medications to stay active

Fraenkel
(29)
2014
USA
	• Relative importance of characteristics of disease modifying drugs for OA
	  o Benefit – 39.44% (most influential factor)
	  o Risk – 26.92%
	  o Cost – 24.89%
	  o Administration – 8.76%
	• Most participants (80%) were willing to try a disease modifying drug under the best case scenario ie. An easy to afford pill with 80% benefit and a risk of mild side effects. In the worst case scenario (hard to afford infusion associated with a risk of serious side effects in which 40% are expected to benefit) 53% of subjects were willing to try the disease modifying medication. Approximately 65% of subjects were willing to try a somewhat affordable medication administered by injection or infusion that benefits 60% of people and is associated with risks of moderate side effects.
	• 5% did not want to perform subcutaneous injections and would only consider disease modifying drugs for OA under the best case scenario
	• 20% were risk sensitive and were willing to take disease modifying drugs for OA under best case scenario, but would start rejecting these medications as risk increased

	• 16.4% rejected disease modifying drugs for OA under all conditions
	• 59.2% had a strong preference for disease modifying drugs for OA across all risk/ benefit scenarios presented
	• Almost 60% of patients are willing to accept substantial risk in order to prevent progression of OA.
	• Respondents could be categorised into 4 groups
	  o 5% that was unwilling to consider any medication administered by injection
	  o 19% that was risk sensitive
	  o 16% that was not willing to consider disease modifying medications under any circumstances

Hauber (30) 2013 USA	• Incremental changes (3%) in the risks of MI (10.00; 95% CI: 8.2-11.8) and stroke (8.90; 95% CI: 7.3-10.5) were assessed as the most important risk outcomes by patients • Patients are willing to accept an increase in bleeding ulcer risk of 0.7 percentage points (95% CI 0.3-2.6%) for an improvement in ambulatory pain from 75mm to 50mm • The acceptable risk associated with a 25mm reduction in ambulatory pain was dependent on the baseline level of ambulatory pain: patients accepted the greatest acceptable risk of adverse events when improving from 25mm to 0mm, a smaller risk when improving from 75mm to 50mm, and the smallest risk when improving from 50mm to 25mm on the VAS pain scale • Patients were willing to accept larger risks in exchange for 25mm improvements in ambulatory pain than for comparable improvements in resting pain suggesting the most important benefit attributes were reducing ambulatory pain • The risk tolerance varies according to the baseline level and type of symptom relief
Kao (31) 2014 Taiwan	• Patients were concerned about medication side effects and would avoid frequent use of medicines. These ideas included harm to the kidney and injecting hyaluronic acid damages the cartilage

Laba (33) 2013 AUS	• Medication side effects, mode of action and treatment schedule had a significant effect on the choice to continue medication • Medication side effects of high BP, heart/ liver/ kidney problems were important • Preferences to continue with OA treatments were influenced by, in order or importance: the possibility of high blood pressure, heart/liver/kidney problems as side effects, out of pocket costs, the possibility of heartburn/ reflux, or stomach ulcer as side effects, treatment schedule, mode of action (slowing OA vs symptomatic pain relief) and the possibility of drowsiness or constipation as a side effect. • Treatment efficacy did not significantly influence patient choices
Rosemann (42) 2006 Germany	• Patients stated that information on side effects in the package inserts of medications was not that important to them, because they were aware that many of the side effects on the package never occurred. • Patients considered opiates to be a medication for people in very poor condition eg. cancer patients, and therefore rejected.
Patient perceived barriers to using medication for OA	

Laba (33) 2013 AUS	• Medication out of pocket costs were important after the side effects of the medication.
Manias (35) 2007 AUS	• Financial constraints impacted patients' ability to pay for the medications. This constraint was further burdened by the expense associated with using complementary products such as glucosamine. • Patients titrated their medications by omitting an analgesic unless their osteoarthritis pain was particularly severe. • Patients highlighted the complexity of taking multiple medications. • Most patients preferred to use only medications to manage OA and not non pharmacologic means, due to ease of using drugs compared to time required to participate in non pharmacologic treatments, lack of motivation, difficulty with transportation
Patient perceived needs related to physiotherapy and exercise therapy	
Patient perception of need for physiotherapy and exercise to achieve better health outcomes	

Alami (21) 2011 Canada	• Exercise therapy considered essential after knee surgery and important in OA to relieve pain and increase muscle strength
Baumann (23) 2007 France	• Benefits from gaining confidence and knowledge of how to self manage pain in other joints • Gaining insight of how others coped with their pain
Chan (25) 2011 Hong Kong	• Patients sought physical therapists for knee OA
Feldman (28) 2010 Canada	• Of patients with chronic arthritis, 26.1% felt they required rehabilitation and the majority of these (96%) did not receive these services • The perceived need for rehabilitation was not associated with level of disability or pain but with a lower level of self efficacy (p=0.007)

Rosemann (42) 2006 Germany	• Patients wanted information about community services including sports groups.
Victor (41) 2004 UK	• Patients with knee OA wanted to achieve better health through taking exercise and losing weight • Participants stated goals in terms of maximising and increasing their daily activity as a strategy to manage their pain
Patient perceived factors and barriers affecting utilisation of physiotherapy and exercise	

Ackerman (20) 2013 AUS	• Disinterest was the most common reason for not participating • Other reasons for non participation included satisfied with current OA management, doubts about the potential personal benefits of participation, lack of support from GP, seeking more definitive treatment (ie. Surgery), concerns about content of the questionnaire • Numerous barriers to participation which included physical limitation (22%), distance/ transport difficulties (22%), work commitments (22%), time commitment required (17%), family commitments/ carer role (12%), other including preferences for course scheduling and/ or venue (20%) • Half the patients preferred the course to be held on a particular day (or days) and were unable to attend if scheduled on a particular day. One quarter had no specific preference or were flexible in terms of course scheduling. Many preferred to attend the course during the day, with few people favouring the evening or weekend • Most people preferred to attend a 6 week course, while similar proportions preferred to receive the self help book only or had no preference • Group based self-management programs are inaccessible for many people with hip or knee OA

Baumann (23) 2007 France	• Beneficial to undertake exercises that took into account their multisite presentation
Brembo (24) 2016 Norway	• Most of the participants did not attend physiotherapy regularly as they felt it was unnecessary and there are other ways of staying active.
Chan (25) 2011 Hong Kong	• Patients with knee OA needed to reduce exercise and or change exercise secondary to pain and adjust movements and activities according to pain ie. Put pants on whilst lying down to avoid bending the knee • They also engaged in exercise to reduce pain or strengthen muscles
Rosemann (42) 2006 Germany	• Directions for exercise from the GP were vague and patients desired more specific instructions. • Pain and lack of mobility were barriers to physical activity. • Lack of patient motivation for physical activity was also a barrier, despite their GP repeatedly trying to motivate them.

Patient perceived needs related to CAM	
Patient perceived need of outcomes from CAM	
Alami (21) 2011 Canada	• Dietary supplements give patients the feeling of being active. Not seen as symptomatic of palliative answer but a more satisfying option, an attempt to "cure the cause" of the illness • Conflicting views on spa therapy – some consider it to have substantial benefit and others consider it a distraction
Asprey (22) 2012 UK	• Acceptability may be maximised by taking into account a number of factors: full information should be provided before treatment begins, flexibility should be maintained in the appointment system and different levels of contact between patients should be fostered, sufficient space and staffing • Patients enjoyed the supportive group environment, shared experience, preference for group environment, reduction in analgesia and positive patient interaction with nurse. • Electroacupuncture was appealing as it facilitated patient control
Brembo (24) 2016 Norway	• Some patients with persistent pain and decreased physical function try alternative treatment options

Chan (25) 2011 Hong Kong	• Patients sought traditional Chinese medicine for knee OA
Rao (39) 1998 USA	• None of the patients said they would forgo conventional therapy for unconventional therapy. Those who tried an unconventional therapy used it to supplement prescribed therapy • Desire for pain relief was the most frequent reason for using unconventional therapy
Patient perception of the risks and benefits of CAM	
Alami (21) 2011 Canada	• Alternative care providers are more accessible and open to discussion, more empathy, spend more time with patients, consider patients globally in their environment
Patient perceived barriers to using CAM for OA	
Asprey (22) 2012 UK	• Patients preferred group clinic organisation, flexibility and availability of a large physical space (patients more relaxed in larger space)

Chan (25) 2011 Hong Kong	• Monetary costs of treatment affected choice of treatment
Patient perceived needs related to joint replacement surgery	
Alami (21) 2011 Canada	• Desired to occur as late as possible. Associated surgical fears – anaesthesia, nosocomial infections, failure concerning poor surgical results.
Brembo (24) 2016 Norway	• When the pain significantly restricted their ability to perform activities of daily living, some participants wanted a referral to an orthopaedic surgeon and strongly valued the experience of the surgeon. Pain was the main reason for considering hip replacement, which was considered a common procedure, with excellent outcomes.

Kwoh (32) 2015 USA	• Among all participants, greater trust in physicians was associated with willingness to have joint replacement surgery • Having a family member or friend who had knee/hip surgery, having a good understanding of joint replacement surgery, perceiving less pain after surgery and perceiving less difficulty walking after surgery were associated with willingness to undergo knee replacement surgery.
Maly (44)	• Patients had concerns about access to joint replacement surgery
Mann (36) 2011 UK	• Patients believed that joint replacement surgery was the only effective treatment • Access to joint replacement was a concern, and patients noted that the clinicians' decisions or advice were not always consistent
McHugh (38) 2007 UK	• One patient, desperate to have his hip replacement operation, spoke about wanting to withhold information about his medical condition (which may have prevented him from having a THR). The THR was seen as the most important thing to this participant and he was willing to risk the aneurysm rupturing to avoid further pain and comorbidity from the hip

O'Hara (37) 2015 USA	• Participants that were waiting to have total shoulder arthroplasty had a strong preference for an experienced surgeon.
Sanders (43) 2004 UK	• Despite patient joint symptoms causing severe disruption to their lives, older patients assumed they would not be considered as appropriate surgical candidates on account of their age, and so did not discuss treatment options with their doctor. Other patients sought joint replacement surgery and were disappointed when the clinician informed them that they were too young to have the operation. • Participants were fearful of poor surgical outcomes from joint replacement. Other reasons for reluctance included weight, comorbidity or caring commitments.
Patient perceived needs related to access to health services	
Patient perceived barriers to access to health services	
Chan (25) 2011 Hong Kong	• Factors affecting choice of medical assistance included perceived treatment efficacy and treatment cost

Davis (26) 2002 USA	• Societal and community issues, such as lack of transportation and lack of support (eg. no bath or assistance for use of a TENS machine) were barriers to the access of health services • Financial constraints (eg. payment for treatment, insurance coverage) affected access to treatment. • Poor access to appropriate health care providers was a patient concern, with lack of continuity. • Patients desired to choose their own providers who could understand their needs.
Douglas (27) 2005 UK	• 75% of patients prefer to attend the hospital site closest to their home rather than their local primary care centre. • 47% of patients did not mind which weekday they came to clinic • Morning appointments were preferred by 58% of patients and afternoon appointments by 16%. Only 2% would choose a weekend or evening appointment
Sanders (43) 2004 UK	• Patients found initial difficulties in getting a specialist referral and experienced problems with long waiting lists.
Patient perception of risks and benefits related to health service access	

Llewellyn-Thomas (34) 1998 Canada	• 57% of patients initially chose a 6 month wait with a 1% mortality risk • No clear association between maximal acceptable waiting time and symptomatic burden • The overall distribution of conditional maximal acceptable wait time scores ranged from 1 to 26 months, with a median of 7 months
Patient perceived need of outcomes from health services	
Mann (36) 2011 UK	• Patients commented that OA appeared to be a low priority in health care • Patients believed that GPs were generally too busy to spend much time discussing OA and were not specialists in arthritis • Patients want access to specialist knowledge and advice as well as access to someone known to them who was knowledgeable about OA eg. Practice nurse, easily accessible, this would avoid bothering the GP unnecessarily
Patient perceived needs related to orthoses and physical aids	
Patient perceived need of outcome from using orthoses and physical aids	

Alami (21) 2011 Canada	• Knee orthoses - Patients appreciated the increased feeling of stability and because of pain relief attributed to heat. Aesthetic concerns and emphasis on the burden of wearing the orthoses • Soles - Considered complimentary options to decrease weight bearing on the affected leg during gait • Gait aid and wheelchair accepted as transient options but less well accepted because they imply old age and loss of autonomy if considered as permanent
Chan (25) 2011 Hong Kong	• Need to use a walking stick and needing to take analgesia prior to going out • Patients learned coping strategies from the media, Internet, physical therapists, doctors and health professionals, as well as from fellow sufferers
Kao (31) 2014 Taiwan	• To relieve knee discomfort, patients used auxiliary devices such as kneecaps and braces and showering in hot water, bathing in hot springs and electrotherapy

McHugh (38) 2007 UK	• Little awareness of the kinds of living aids or home adaptations which were available through social services or by assessment from an occupational therapist or nurse by patients in the waiting list for joint replacement • Having a joint replacement meant time off work with some not entitled to sick time
Patient perception of risks and benefits related to orthoses and physical aids	
McHugh (38) 2007 UK	• Having a joint replacement meant time off work with some not entitled to sick time
Thomas (40) 2013 UK	• Patients with foot OA want desirable/ fashionable footwear. Concerns about bunions showing

Supplementary Document 1: Search Strategy for MEDLINE

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 prosthe*)).tw.

29. (arthroplast* or hemiarthroplast*).tw.

30. arthroplasty/ or arthroplasty, replacement/ or arthroplasty, replacement, hip/ or arthroplasty, replacement, knee/ or hemiarthroplasty/ or arthroscopy/

31. ((anti-inflammatory or antiinflammatory or analgesic) adj3 (agent* or drug* or medic*)).tw.

32. ((nonsteroid* anti-inflammatory or nonsteroid* antiinflammatory or non steroid* anti-inflammatory or non steroid* antiinflammatory) adj (agent* or drug* or medic*)).tw.

33. pain killer*.tw.

34. analgesics/ or analgesics, non-narcotic/ or acetaminophen/ or ibuprofen/ or exp anti-inflammatory agents, non-steroidal/ or analgesics, short-acting/

35. Analgesics, Opioid/

36. steroid*.tw.

37. Steroids/

38. Prednisolone/

39. (disease modifying anti rheumatic adj (agent* or drug* or medic*)).tw.

40. antirheumatic agents/ or azathioprine/ or chloroquine/ or gold sodium thiomalate/ or gold sodium thiosulfate/ or hydroxychloroquine/ or methotrexate/ or sulfasalazine/

41. Biological Products/

42. Tumor Necrosis Factors/

43. Tumor Necrosis Factor-alpha/

44. Interleukin 1 Receptor Antagonist Protein/

45. Infliximab.tw.

46. Etanercept.tw.

47. Certolizumab.tw.

48. Golimumab.tw.

49. Interleukin 1 inhibitor.tw.

50. Anakinra.tw.

51. Canakinumab.tw.

52. Interleukin 6.tw.

53. Tocilizumab.tw.

54. CD-20.tw.

55. Rituximab.tw.

56. Co-stimulatory blockade.tw.

57. Abatacept.tw.

58. biologic*.tw.

59. tnf.tw.

60. Diphosphonates/

61. Bisphosphonate*.tw.

62. Vitamin D/

63. Cholecalciferol/

64. vitamin D.tw.

65. Calcium/

66. Calcium.tw.

67. self-help devices/ or wheelchairs/

68. exp Dependent Ambulation/

69. canes/ or crutches/ or orthotic devices/ or braces/ or walkers/

70. (walking adj3 (cane* or frame* or aid*)).tw.

71. self help devices.tw.

72. assistive devices.tw.

73. or/4-72

74. (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.

75. Needs Assessment/ or "Health Services Needs and Demand"/ or Health Services Accessibility/

76. 74 or 75

77. ((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.

78. "patient acceptance of health care"/ or patient preference/ or patient satisfaction/ or Patient-Centered Care/ or Health Knowledge, Attitudes, Practice/

79. 77 or 78

80. ((household or out of pocket) adj3 expen*).tw.

81. "cost of illness"/ or health expenditures/ or exp "fees and charges"/

82. Waiting Lists/

83. Rural Health/ or Rural Population/

84. Urban Health/ or Urban Population/

85. Primary Health Care/

86. secondary care/ or tertiary healthcare/

87. Vulnerable Populations/

88. exp Culture/

89. communication barriers/

90. (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.

91. 80 or 81 or 82 or 83 or 84 or 85 or 86 or 87 or 88 or 89 or 90

92. 3 and 73 and 76 and 79 and 91

93. 78 and 92

94. exp osteoarthritis/

95. (degen* adj4 arth*).tw.

96. osteoarth*.tw.

97. coxarth*.tw.

98. gonarth*.tw.

99. 94 or 95 or 96 or 97 or 98

100. 93 and 99