Systematic scoping review of patients' perceived needs of health services for osteoporosis.

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CONFLICT OF INTEREST

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ABSTRACT:

Purpose: Health service planners, administrators and providers need to understand the patients' perspective of health services related to osteoporosis to optimize health outcomes.

Aim: To systematically identify and review the literature regarding patients' perceived health service needs relating to osteoporosis and osteopenia.

Methods: A systematic scoping review was performed of publications in MEDLINE, EMBASE, CINAHL and PsycINFO (1990-2016). Descriptive data regarding study design and methodology were extracted and risk of bias assessed. Aggregates of patients' perceived needs of osteoporosis health services were categorized.

Results: 33 studies (19 quantitative and 14 qualitative) from 1027 were relevant. The following areas of perceived need emerged: (1) Patients sought healthcare from doctors to obtain information and initiate management. They were dissatisfied with poor communication, lack of time and poor continuity of care. (2) Patients perceived a role for osteoporosis pharmacotherapy but were concerned about medication administration and adverse effects. (3) Patients believed that exercise and vitamin supplementation were important, but there is a lack of data examining the needs for other non-pharmacological measures such as smoking cessation and alcohol. (4) Patients wanted diagnostic evaluation and ongoing surveillance of their bone health.

Conclusions: This review identified patients' needs for better communication with their healthcare providers. It also showed that a number of important cornerstones of therapy for osteoporosis, such as pharmacotherapy and exercise, are identified as important by patients, as well as ongoing surveillance of bone health. Understanding patients' perceived needs and aligning them with responsive and evidence-informed service models is likely to optimize patient outcomes.

INTRODUCTION

Osteoporosis is increasingly being recognised as an important public health concern due to an aging population and rise in chronic diseases[1]. It is estimated that one in two women and one in five men over the age of 50 will sustain a fracture due to osteoporosis[2]. Fragility fractures related to osteoporosis are associated with significant morbidity and mortality. The direct medical costs of this global health burden are substantial, amounting to an estimated $17 billion in the United States in 2005[3], € 37 billion in the European Union in 2010 [4] and more than $9 billion in China in 2010 [5]. This is projected to surpass $25 billion by 2025[3,5,6].

To close the evidence-practice gap in osteoporosis management and address the burden of osteoporosis[6,7], several peak organisations have developed clinical practice guidelines to guide clinicians in optimising bone health and managing osteoporosis[8-12]. Recent strategies have been implemented to improve the uptake of evidence-based recommendations, such as education programs, fracture-liaison services, orthogeriatric models of care and audits of healthcare services[13-15]. However, despite these measures, the management of osteoporosis and bone health following fragility fractures remains inadequate[16-18]. Previous studies have shown that just up to 25% of patients identified as high risk had further investigations for osteoporosis and less than 20% of patients with osteoporosis or a history of fragility fractures received treatment to prevent future fractures[15-17,19,20].

Optimal osteoporosis outcomes, for the patient and health service, depend on a variety of factors at multiple levels – from health policy through to patients' self-management behaviours: all of these factors may affect the effective implementation of guidelines and models of care[21]. Understanding why management deviates from guidelines so frequently is important to improve bone health outcomes. A recent seminal report by the International Osteoporosis Foundation[6] has summarised current international gaps in quality service delivery for people with poor bone health and has suggested strategies from a health services and policy perspective for improvement. However, these issues are not considered through the lens of the consumer. As management requires the patient to access and use healthcare services, identifying their perceived needs may provide insight into why optimal management does not occur, or is not

sustained (of particular relevance to osteoporosis management). It may also suggest more effective strategies for healthcare providers and policy makers for implementing consumer-centred strategies and promoting patient-centred care: taking the patients perceived needs into account may inform clinical decision making, helping doctors to optimise osteoporosis treatment. Although there are published systematic reviews that examine patients' health beliefs relating to osteoporosis[22] or their experience of living with osteoporosis[23], these do not examine the patients' perceived needs of health services. There have also been several studies that explore the patients' perspective and perceived needs of health services for osteoporosis, either directly or indirectly but no review has been performed to identify and summarise the existing literature. Therefore, we performed a systematic scoping review to identify the literature regarding patients' perceived needs for health services for osteoporosis and osteopenia management.

METHODS

A systematic scoping review was performed to identify what is known about patients' perceived health service needs for osteoporosis and osteopenia within a larger project examining the patients' perceived needs relating to musculoskeletal health[24]. Throughout, we refer to 'osteoporosis', which is inclusive of osteopenia. Given the breadth of the topic, a systematic scoping review, based on the framework proposed by Arksey and O'Malley[25], was conducted to comprehensively explore of the patients' perspective, map the existing literature and to identify gaps in the evidence[26,27].

Search Strategy and Study Selection

An electronic search of MEDLINE, EMBASE, CINAHL and PsycINFO was performed to identify studies examining patients' perceived needs relating to osteoporosis health services between January 1990 and July 2016. This time period was chosen to include relevant studies examining the current patient perspective. The search strategy was developed iteratively by an academic librarian, clinical researchers (Rheumatologists and Physiotherapists) and a healthcare organisation representing consumers with osteoporosis and musculoskeletal disorders. It combined both text words and MeSH terms to capture information regarding the constructs of

osteoporosis and bone health, patients' perceived need(s), and factors related to health services. The term "patients' perceived needs" was used to broadly capture the patients' perception of their capacity to benefit from services, including their expectations of satisfaction with and preferences for various services[28]. The term "health services" includes "services relating to the diagnosis and treatment of disease, or the promotion, maintenance and restoration of health", as described by the World Health Organisation[29]. The term "health service needs" describes the patients' perception of their capacity to benefit from services relating to the diagnosis and treatment of osteoporosis, or the promotion, maintenance and restoration of health, relating to osteoporosis. The detailed search strategy for MEDLINE is provided in the Supplementary Appendix.

Two investigators (LC and PS) independently assessed all the titles and abstracts of the studies identified by the initial search for relevance. The initial screening of manuscripts identified by the search strategy was designed to be as inclusive as possible to identify relevant studies, within the specific inclusion and exclusion criteria to capture the breadth of the literature. The reference lists of retrieved articles and review articles were also manually assessed for further studies for inclusion. To be included in the review, studies had to: (1) concern patients older than 18 years and at risk of osteoporosis or having osteoporosis (either diagnosed by a physician, based on bone densitometry results, or individuals taking medications for osteoporosis); (2) report on patients' perceived needs of health services; (3) concern osteoporosis (either primary or secondary), osteopenia or bone health and (4) full-text articles. Both qualitative and quantitative studies were included to provide an in-depth review of the topic. Only studies in the English language were retained due to resource constraints. Studies that appeared to meet the inclusion criteria and relevant reviews were retrieved and the full text was assessed for relevance by two investigators (LC and PS). Any disagreements in the inclusion of studies were resolved through consensus or reviewed by a third investigator (AW).

Data extraction and analysis

Two investigators (LC and PS) independently extracted the data from relevant studies using a standardised data extraction form developed for this scoping review. The

included studies were described and reported according to: (1) author and year of publication; (2) study population (patient age and gender, population source, population size and definition of osteoporosis); (3) primary study aim; and (4) description of the study methods. Two authors (LC and PS) independently reviewed and extracted relevant data from the included studies using the principles of meta-ethnography to synthesise qualitative data[30]. This involved a process of identifying key concepts from the included studies and reciprocal translational analysis was undertaken to translate and compare the concepts from individual studies to other studies and gradually explore and develop overarching themes [31]. Importantly, reciprocal translational analysis allows for the development of a concept or theme by considering different viewpoints related to the same issue, described in different ways. In the first stage, one author (PS) 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, another author (LC) independently reviewed the studies and further developed the framework of themes and concepts. In the third stage two senior authors (FC and AW) with over 10 years of clinical rheumatology consultant-level experience independently reviewed the framework of concepts and themes to ensure clinical meaningfulness and face validity.

Methodological Quality Assessment

To assess the methodological quality of the included studies, two reviewers independently assessed all of the included studies (LC and PS). For qualitative studies, the Critical Appraisal Skills Programme (CASP) tool was used[32]. The risk of bias tool was utilised to assess the external and internal validity of quantitative studies: low risk of bias of quantitative studies 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[33]. The reviewers discussed and resolved disagreements through consensus. Any disagreements in scoring were reviewed by a third reviewer (AW).

RESULTS

Overview of studies

The search strategy identified 1030 studies, of which 33 articles met the inclusion criteria for this review [34-67]. A PRISMA flowchart detailing the study selection is shown in Figure 1. The descriptive characteristics of the included studies are shown in Table 1.

Of the included studies, 20 were from North America[34,35,37-40,43,45-48,52,54-57,59,60,64,65], 6 from Europe [41,42,50,53,61,67], 3 from the United Kingdom[36,49,51], 1 from South America [66] and 1 from the Middle-east [63]. There was 1 multi-centre study[44]. A total of 16975 patients were included; the sample size of the quantitative studies ranged from 21 to 3438, with a median of 765 and the sample size of the qualitative studies ranged from 14 to 164, with a median of 25. Across the studies, 95% of the participants were female: 22 studies examined only female participants[34,36,38,40,41,44-50,52,53,58,60,61,63-67] and the remaining 11 studies evaluated mainly women[35,37,39,42,43,51,54-57,59]. The mean age of participants was 68 years. Eight studies recruited participants with a previous fragility fracture or at high risk of osteoporotic fractures and 6 studies included patients requiring prescription medications, with or without a previous history of fractures. Only 4 studies provided details regarding other co-morbidities: 2 studies reported that more than 50% of their participants had less than 1 co-morbidity [51,61] and 2 studies had more than 70% of participants with more than 2 co-morbidities[42,63].

Nineteen studies used quantitative methods[34,37,39,40,42,44,46,47,50-52,58,59,61,63-67], all of which were cross sectional surveys; of these, 13 used questionnaires[37,39,42,46,47,50,51,58,61,63,65,67], 5 used surveys [34,40,44,59,64] and 1 used interviews[52]. Fourteen used qualitative methods[35,36,38,41,43,45,48,49,53-57,60]; of these, 10 used interviews[35,36,38,41,48,49,54-57], 4 used focus groups[38,43,45,53] and 1 used video recordings[60]. There were no mixed methods studies.

The inclusion criteria for study participants varied across studies. Patients were classified as having osteoporosis based on bone densitometry in seven studies[34,41,46,48,53,65], requiring prescription medications in six studies[42,45,52,59,63,66] or on the basis of previous fragility fractures or high risk of osteoporotic fractures in eight

studies[37-39,47,54-56,61]. The diagnosis of osteoporosis or osteopenia was unspecified in 13 studies[36,40,43,44,49-51,57,58,60,64,67].

Quality of studies

Quality assessments of the included studies are presented in the Supplementary Appendix, Figures 1 and 2. The quality of qualitative studies was poor, especially for CASP criteria 4 to 6 (Supplementary Appendix, Figure 1). The quantitative studies were of low quality: 18 studies were at high risk of bias and 1 study was at moderate risk of bias (Supplementary appendix, Figure 2). These scores for both qualitative and quantitative studies reflected potential biases with participant recruitment and data collection.

Results of review

Four main areas of patients' perceived needs of health services for osteoporosis emerged from this review.

Patients' perceived needs of healthcare providers in the management of their bone health and osteoporosis (Table 2)

Patient preference for consulting medical practitioners and their role

Eight studies identified patients' preference for seeing a medical practitioner for osteoporosis and their perceived role[35,38,41,43,45,48,49,56]. Four studies found that patients sought care from a medical practitioner for their bone health[43,45,48,49]. Two studies reported that patients believed and trusted medical specialists such as endocrinologists and rheumatologists more than their primary care physician, and they perceived their specialists as being more interested in their bone health than primary care providers[35,43]. Feldstein found that patients who had sustained a fracture advocated for standardized protocols for integrating and involving medical specialists in the management of osteoporosis[38]. The role of the medical practitioner was perceived to perform a thorough examination[41], provide osteoporosis information and education[38,41,49,56], initiate screening for osteoporosis[38,56], prescribe and monitor treatment[38,45,48,56] and provide support for optimal self management[45].

Desirable characteristics of the medical practitioner

Four studies reported on the desired characteristics of medical practitioners in the management of osteoporosis[36,41,45,52]. Besser found that patients wanted to be involved with decisions related to osteoporosis treatment[36]. Lau and Rizzoli reported the patients wanted follow up from healthcare providers for support and monitoring of medications[45,52]. Also, patients wanted their osteoporosis to be taken seriously by their practitioners[41] and to be able to discuss medication problems and concerns[45]. Lau reported that patients wanted non-judgemental care [45].

Dissatisfaction with, or concerns about, medical and non-medical practitioners

Six studies identified patients' dissatisfaction and concerns with medical practitioners relating to their osteoporosis management[35,36,43,46,48,49]. Patients perceived poor communication, lack of an adequate explanation of the diagnosis and poor continuity of care to be barriers to a good relationship with their doctor[36,46]. Patients were dissatisfied with the lack of time during consultations, and felt that they were unable to ask questions or raise issues with medications with their physicians[35,36,43]. Furthermore, they felt that their primary care providers were dismissive of their concerns about osteoporosis[35]. Patients were disappointed with the strong focus on medications and expressed distrust when medical practitioners were too quick to recommend medications, rather than adopt a more holistic approach to care, inclusive of non-pharmacologic options[48,49]. Moreover, patients reported inconsistent recommendations from different practitioners, and in particular they found the advice from other disciplines of healthcare, such as nutritionists, physiotherapists and chiropractors to be contradictory, sporadic and not forthcoming[35].

Patients' needs related to pharmacotherapy for osteoporosis and bone health (Table 3)

Perceptions and roles of medications

Eleven studies examined the patients' preference for medications and the perceived role of pharmacotherapy[36,37,39,45,47,48,54,56,59,61,65]. While some studies found that patients had a preference for pharmacological management of osteoporosis[36,37,39,45,54,56,59], other studies did not[45,48,54,56]. The patients who were more

willing to take medication had been told of the diagnosis of osteoporosis[47,65] and had previous bone mineral density (BMD) testing[47], believed they were susceptible to fractures[59], had a good relationship with their doctor or trusted their physicians[54,59] and believed in the effectiveness of medications[65]. The role of pharmacotherapy was perceived to help eliminate symptoms, help avoid further deterioration in bone health, provide extra strength for the bone and improve bone density[48,54]. A single study that compared patients' predilection for pharmacotherapy compared to hip protectors in high risk patients found that although patients preferred bisphosphonates for the management of their osteoporosis, older patients were more likely to avoid prescription medications and preferred hip protectors[39]. In contrast, several studies reported that patients did not prefer pharmacotherapy for osteoporosis management[45,48,54,56]. Mauck reported that most women who were admitted to a tertiary hospital after a fragility fracture were either unaware of osteoporosis or had never considered pharmacological treatment[47]. Some patients viewed osteoporosis as a consequence of aging and did not perceive a need for medications[48] and some patients wanted a drug holiday from bisphosphonate treatment[56]. Also, some patients preferred lifestyle modifications rather than pharmacotherapy for osteoporosis management[45,48,56].

Concerns about medications

There were twelve studies that reported the patients' concerns with osteoporosis medications[34,36,41-43,45,48,53,54,60,65,66]. Patients who believed they had good health were concerned about taking medications for a condition that was otherwise asymptomatic[53,60]. Those with a family member who had osteoporosis with no complications were less likely to perceive a benefit with pharmacotherapy[53,60]. Moreover, patients were unwilling to take medications if they had family members or friends who had experienced adverse events, or if they heard about side effects from the media[34,45,48]. Potential side effects from medications were a major concern for many patients[34,36,41-43,45,48,53,54,60,65,66], as well as possible drug interactions from polypharmacy[36,66], the potential for addiction and overdosing[36]. In particular, some patients had specific concerns including the potential for jaw osteonecrosis, gastrointestinal side effects, breast and oesophageal cancer, thrombotic effects and cardiovascular events[34,42,45,53,66]. Patients also reported a dislike of chemicals[36,45], distrust of medications[65] and of pharmaceutical companies[36]. Dissatisfaction with

their doctor or the physician's attitude were other reasons for patients to not want to pursue pharmacotherapy for the management of osteoporosis[54,66]. Furthermore, Iversen reported that patients found the method of medication administration and instructions difficult to understand and remember[43].

Preferable therapeutic attributes of medications

Patients' preferred therapeutic attributes of osteoporosis pharmacotherapy were also examined through this review[40,42,44,45,50-52,58,63,64,67]. Patients wanted osteoporosis medications to be effective[40,44,64], to not interact with other medications[52], have fewer side effects[52], and be easier to administer[44,52,64]. A single study evaluating combination packaging of bisphosphonates and calcium supplementation found that patients preferred the ease and convenience of combination packaging[67]. Some studies found that patients preferred weekly to daily or monthly dosing[40,44,58,64], however, other studies reported a preference for monthly administration[42,66].

Patients' perceived needs of non-pharmacological management of osteoporosis (Table 4)

Four studies examined the patients' perceived needs of non-pharmacological management of osteoporosis[37,38,45,57]. Patients' preference for calcium and vitamin D supplementation were examined by four articles[37,38,45,57], which found that patients wanted these supplements for osteoporosis management. Patients expressed more willingness and comfort with taking supplements than prescription medication[38] and believed them to be more natural and safe[45]. Bogoch and Sale and found that patients see a role for exercise for osteoporosis management[37,57]. There were no studies identified that examined the patients' perceived needs of other non-pharmacological strategies such as smoking cessation, attitudes to interventions related to falls prevention and avoidance of excessive alcohol.

Patients' perceived needs of investigations for osteoporosis (Table 5)

Three studies described patients' perceived need for investigations for the diagnosis of osteoporosis[48,53,56]. Patients saw a role for bone densitometry testing for diagnostic evaluation[48,56]. Rothmann found that patients interpreted screening for osteoporosis as

an opportunity to get reassurance about bone health and to optimise their own general health[53]. Three studies described patients' perceived need for investigations for ongoing surveillance of bone health[36,48,56]. Patients wanted feedback from bone density scans to evaluate the efficacy of pharmacotherapy[36,48]. Sale reported that patients felt that had to "nag" their physicians and follow up their own results[56].

DISCUSSION

This systematic scoping review identified 33 studies that explored patients' perceived health service needs for osteoporosis. We identified specific health service needs among people with osteoporosis or osteopenia, highlighting opportunities for specific enhancement in models of service delivery for these conditions to ensure they continue to evolve in a patient-centred manner.

This review found that patients sought care from medical practitioners for the management of their osteoporosis[35,43,45,48,49]. In particular, patients tended to prefer management from specialists over primary care physicians. This is similar to other musculoskeletal conditions, such as low back pain[68,69], and may reflect a lack of confidence or prioritisation by general practitioners in the management of bone health[70]. This may be attributed to limited knowledge of primary care providers[70], and suggests a need for future targeted education programs to bridge this gap, which have been shown to improve patient outcomes in osteoporosis as well as other chronic illnesses such as diabetes, asthma and congestive cardiac failure[71,72]. Patients' expectation of healthcare providers was to perform a thorough examination, provide osteoporosis information and education, initiate screening for osteoporosis and to prescribe and monitor treatment[38,41,45,48,49,56]. They wanted supportive and non-judgemental physicians[35,45,52], which enabled and promoted shared-decision making. Indeed, this represents a key enabler to more effective self-management and sustainability to positive bone health behaviour change. They expressed dissatisfaction with the lack of time given by physicians, poor communication[35,36,43] and the inconsistent messages from different healthcare providers[35]; again highlighting the need for standardisation in cross-discipline education. Additionally, the dismissive approach, strong focus on pharmacotherapy and lack of continuity of care from healthcare providers were other areas of discontent among

patients[35,36,43,46,48,49]. It also underscores the patients' preference for patient-centred care and reinforces the need for clinicians to provide holistic care to improve the provider-patient relationship, which may facilitate improved uptake of osteoporosis clinical guidelines. This desire for improved communication from healthcare providers and holistic care is a common perceived need of patients with other chronic musculoskeletal conditions, including osteoarthritis, low back pain and inflammatory arthritidies[24,73].

Patients perceived a role for medications in the management of osteoporosis[36,37,39,45,54,56,59]. This is congruent with current clinical practice guidelines for osteoporosis which emphasise the use of pharmacotherapy[8-12], based on strong evidence for a number of effective medications in improving BMD and reducing fracture risk[74]. In particular, this review found that individuals who were aware of the diagnosis of osteoporosis[47,65], those who believed they were susceptible to future fractures[59], or had previous evaluation of their bone health[47] had a preference for medications. Furthermore, patients with a good relationship with their healthcare provider were more likely to have a preference for pharmacotherapy[54,59] and this may reflect a more patient-centred approach to communication and shared therapeutic decision-making. Despite this perceived need for pharmacotherapy, there are high rates of treatment non-adherence for osteoporosis, with an estimated 50% of patients not taking medications by 12 months[75]. Educating patients regarding the benefits and rationale for effective pharmacotherapies for osteoporosis, a largely asymptomatic condition in the absence of fracture, may help to improve patient adherence with therapies and health outcomes, particularly a reduction in fracture risk[76,77]. This contrasts with other chronic musculoskeletal conditions such as osteoarthritis, low back pain and inflammatory arthritis, where the perceived need for pharmacotherapy is often driven by a desire for symptom and pain control and maintenance of function and mobility [24,73,78-80]. Furthermore, addressing patients' concerns regarding pharmacotherapy, coupled with a broader approach to care that addresses lifestyle factors and support for effective self-management choices, may improve uptake of medications and health outcomes.

This review identified a number of patient beliefs regarding pharmacotherapy that may impact of adherence to osteoporosis pharmacotherapy. These included concerns

regarding medication side effects, the potential for addiction and overdosing, and the confusion and difficulty with the method of administration of medications[34,36,41-43,45,48,53,54,60,65,66]. Furthermore, patients report a lack of knowledge about medications and they desire more health information[38,43,45,48,81,82]. Medication non-adherence is also a growing concern in other chronic conditions, such as cardiovascular disease[83] and diabetes mellitus[84]. Poor adherence to medications is often multifactorial, and may be due to patient, disease, medication, socioeconomic and healthcare system-related factors[85]. These areas of concern for osteoporosis pharmacotherapies may be addressed by multimodal interventions, including the provision of patient education and the development of novel systems to allow the mode of administration of medications to be more acceptable to patients and the use of technologies to prompt taking medications. Furthermore, the patients' beliefs and preferences for pharmacotherapy reported by the included studies need to be contextualised by healthcare providers. These findings demonstrate the breadth of patients' beliefs and preferences, and they may not apply to an individual patient. Clinicians should be cognisant of providing a tailored management approach to each specific patient, which may also improve the provider-patient relationship and foster a better therapeutic relationship.

Another finding from this review is that although some patients preferred medications[36,37,39,48,54,56], they also perceived a need for lifestyle modifications and non-pharmacological therapies, such as exercise and vitamin supplementation to improve bone health[37,38,45,57]. These non-pharmacological therapies were seen to be associated with lower-risk than prescription medications[38,86]. Patients expressed dissatisfaction with the strong focus on pharmacotherapy from medical practitioners[48]. It appeared that driving the need for non-pharmacological therapies was the desire for a more holistic approach to healthcare management[36]. Despite exercise being a cornerstone therapy for the management of osteoporosis, a relatively smaller volume of literature was identified relating to patients' needs regarding exercise. This represents an important area for future exploration given the under-utilisation of exercise among people with osteoporosis. Capitalising on this need may also improve the relationship between providers and patients and improve osteoporosis outcomes. Integrating the patients' perceived needs of non-pharmacological management will improve guideline adherence, especially as these

recommend[8-12], based on evidence[74,87-89] the use of physical therapy and vitamin D and calcium supplementation in osteoporosis management. However, there is a paucity of data regarding patients' perceived needs of other non-pharmacological lifestyle measures which may influence bone health, such as smoking cessation, attitudes to interventions related to falls prevention and avoidance of heavy alcohol: future research is required.

Clinical practice guidelines suggest the use of bone densitometry for the diagnosis of osteoporosis, to determine risk and need for therapy in people who have not sustained minimal trauma fractures[90]. This aligns with the findings of this review regarding the patients' perceived need of investigations for osteoporosis for diagnostic evaluation, and also for ongoing surveillance of the efficacy of pharmacotherapy[36,48,53,56]. Yet in spite of this, previous studies have found low rates of investigation of bone health in high-risk patients[18], thus, underscoring a lost window of opportunity to improve the uptake and adherence to pharmacotherapy. However, these studies included mainly older female participants, known to be at increased risk of osteoporosis: whether these results are generalizable to the perceived need for investigations in male patients with osteoporosis and younger women are unknown.

This review needs to be interpreted in light of a number of limitations. First, the results of this review have been inferred from heterogeneous studies that evaluated different study questions and had different inclusion criteria for participants. Furthermore, the majority of included studies were conducted in English-speaking, developed countries and examined elderly females. Thus, the results may not be generalizable to men, younger populations, or people of different ethnicities and economies. Although our search strategy encompassed both primary and secondary osteoporosis, there were no studies identified that examined other high-risk groups such as those with long-term glucocorticoid use, end-stage renal failure and other secondary causes of osteoporosis. Moreover, many of the included studies were susceptible to bias, particularly regarding participant recruitment and data collection, as more interested patients may be inclined to participate in these studies. Also, some studies that evaluated pharmacotherapy for osteoporosis were funded by the pharmaceutical industry and many others did not acknowledge sources of funding or state the influence of funding on the study outcomes. These limitations in study

quality highlights a need for future high quality studies to confirm the findings in this review to better understand the patient's perceived needs for osteoporosis health services.

Despite these limitations, this review also has many strengths. A comprehensive scoping review was conducted across four complementary databases and included both qualitative and quantitative studies to capture the breadth of the existing literature. The rigorous and reproducible nature of our methods therefore aligns with the intent of a systematic literature review, demonstrating a notable strength in our approach compared to narrative scoping reviews. The inclusion of qualitative studies provides invaluable insight into patient beliefs and attitudes, and is particularly suitable for exploring biopsychosocial paradigms. Furthermore, several common themes emerged from the included studies, irrespective of study design or study quality, thus, this triangulation of data adds weight to the validity and credibility of the data. Additionally, participants were drawn from across care settings: from the community, from both primary care settings and hospital settings.

This systematic scoping review has identified patients' needs for improved health service delivery and better communication from healthcare professionals. Despite concerns regarding medication administration, side-effects and compliance, patients have identified that osteoporosis pharmacotherapy is important. Patients also perceive a need for vitamin supplementation, exercise and ongoing surveillance of bone health. These findings may be unexpected given the low rates of screening and treatment for osteoporosis. Moving forward, the results from this review reinforce the need to improve the education provided not only to patients but also to cross-discipline healthcare practitioners regarding osteoporosis care. Workforce capacity building initiatives need to address the knowledge and skill deficits not only in pharmacologic management, including availability of different administration regimes for various therapies, but also important non-pharmacologic interventions like appropriate exercise and positive lifestyle choices. Given access limitations in many countries to medical specialists, capacity-building initiatives should be targeted in primary care settings. For consumers, education about the impact of osteoporosis and fractures remains critical to shift unhelpful nihilistic beliefs that the condition is an inevitable part of ageing and the risk-benefit balance of adherence of therapy. There

results confirm that clinicians need to provide patient-centred care through improved communication with patients, providing individualised information regarding the diagnosis and management of osteoporosis, encouraging multi-disciplinary shared care models and the use of decision aids to facilitate shared-decision making. Moreover, given that poor treatment uptake is a significant practice gap in osteoporosis care, patient representatives should be involved in developing clinical practice guidelines and management initiatives to incorporate the patient perspective to develop patient-focused strategies, which may result in improved therapeutic relationships and compliance. The effects of this partnership will need to be evaluated to assess whether this ultimately translates into improved osteoporosis outcomes. These findings align well with the recent International Osteoporosis Foundation 2016 report[6], and together with the results from this review, provides important strategies for improving health services for people with bone health impairments from multiple perspectives, which are critical to consider in any system-level reform initiatives.

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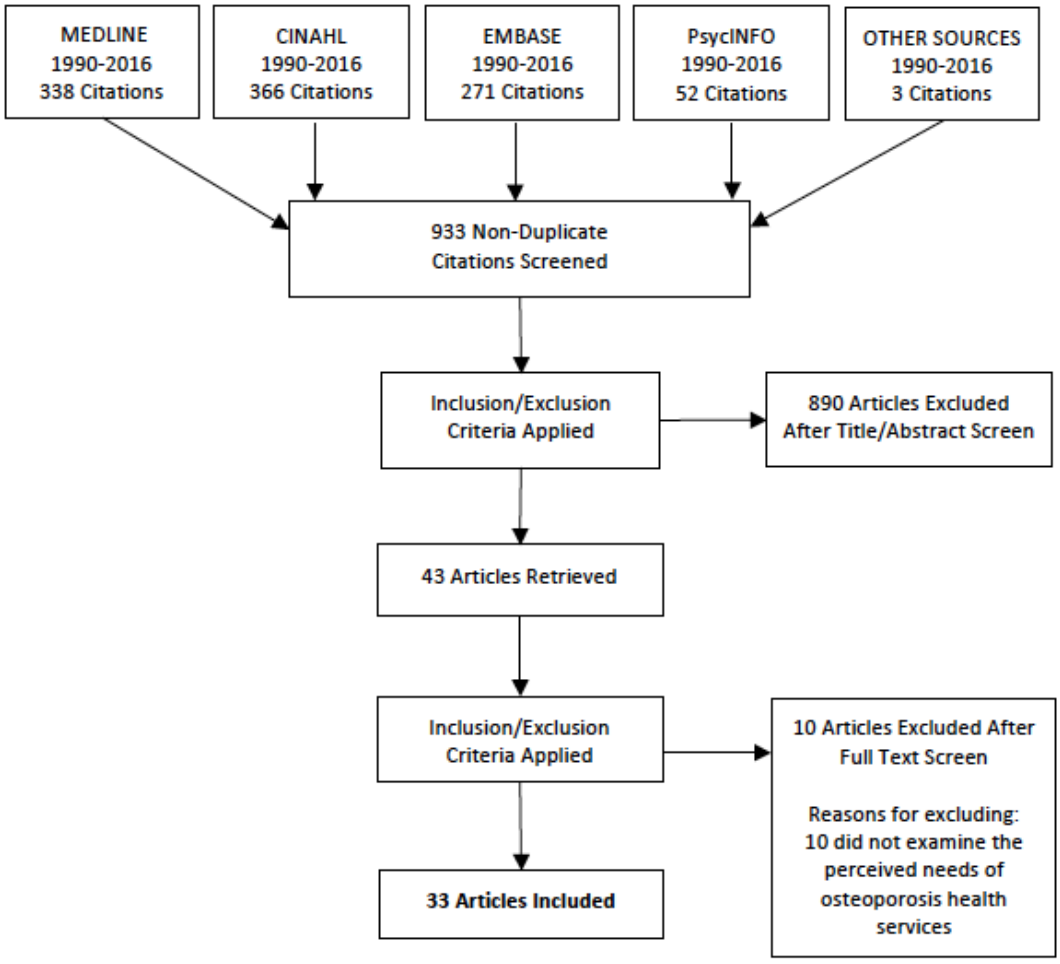

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Table 1. Descriptive characteristics of included studies

Author, Year, Country	Definition of osteoporosis	No. of participants	Source of participants	Age and gender	Primary Study Aims	Study design
Besser 2012 UK [36]	Diagnosed with osteoporosis/ osteopenia (criteria unspecified) for >6 months and prescribed osteoporosis medication.	14	Rheumatology clinic and osteoporosis screening unit at a teaching hospital	Mean age 69 100% female	To inform the development of a psychological intervention to increase adherence to treatment. The study aimed to investigate the osteoporosis patients' perceptions of their illness and medications to provide an evidence base for investigating adherence and how to improve it.	Qualitative: semi-structured interviews and drawings
Bogoch 2008 Canada [37]	Women aged ≥ 40 years or men ≥ 50 years	166	Fracture clinic of a large teaching hospital	Mean age of men 65 (SD 10.1) and	To provide information for practitioners regarding osteoporosis- related needs of	Quantitative: questionnaires

	who had sustained a fragility fracture of the wrist			women 64.8 (SD 13.5) 81% female	patients who present with low-trauma wrist fractures and are at high risk of subsequent hip fracture	
Feldstein 2008 USA [38]	Patients who had had a fragility fracture with no osteoporosis management in prior 12 months	67	Health maintenance organization. 10 patients.	Age greater > 67 years 100% female	To gain perspective on an outreach program and barriers to care for osteoporosis treatment.	Qualitative: interviews and focus groups
Fraenkel 2006 USA [39]	Individuals at high risk for an osteoporotic hip fracture (Fracture	76	Patients who recently (within 2 weeks) had a DEXA scan were recruited from 6 centres	Mean age 78 (SD 5) 95% female	To determine older adults' treatment preferences for osteoporosis comparing bisphosphonates and hip protectors	Quantitative: questionnaires

	Index Score > 7)		performing bone densitometry			
Gold 2006 USA [40]	Women diagnosed with osteoporosis by a physician	617 in the preference study	Patients who were a part of the Risendronate Claims Study were sent an email invitation.	Mean age 67.3 (SD 9.4) 100% females	To determine how patients' preferences for weekly vs monthly bisphosphonate therapy is influenced by their knowledge of the medication's proven fracture efficacy.	Quantitative: online survey
Hansen 2014 Denmark [41]	Women with BMD T score < - 2.5, no previous fracture with prescription for osteoporosis medication	15	Patients undergoing DXA scans at participating hospitals were recruited	Median age 72 (range 65-79) 100% female	To examine the experiences of women living with osteoporosis during the first 6 months after diagnosis.	Qualitative: interviews
Hiligsman 2014	Patients with or at risk of	257	Consecutive patients were recruited	Mean age 67.1 (SD 10.4)	To evaluate the preferences of patients with, or at risk of,	Quantitative: questionnaires

Netherlands [42]	osteoporosis to whom medication or lifestyle changes were proposed		during outpatients' clinics in 2 Belgian osteoporosis centres.	83.3% female	osteoporosis for medication attributes, and to establish how patients trade between these attributes	
Iversen 2011 USA [43]	Patients with diagnosed osteoporosis (criteria unspecified) on treatment for osteoporosis.	32	Participants recruited via advertisements in a tertiary hospital medical center newsletter.	Age range 65 – 85 93% female	To determine factors influencing adherence to osteoporosis medications.	Qualitative: focus group discussions
Keen 2006 Multi-centre (UK, Germany, Spain, Italy	Physician diagnosis of postmenopausal osteoporosis	1248	Women from 5 European countries were recruited. Recruitment details unspecified.	Mean age 66 100% female	To determine participant preference for weekly vs monthly bisphosphonate therapy for osteoporosis after being informed about differences in fracture	Quantitative: survey

and France) [44]					efficacy	
Lau 2008 Canada [45]	Post-menopausal women taking prescription or over the counter medications for osteoporosis (definition unspecified)	37	Recruited by family physicians, geriatrician, rheumatologist and community pharmacists	Age distribution not specified. 100% female	To examine patients' perceptions of osteoporosis medications, reasons for non-adherence to therapy and effectiveness of strategies to improve adherence.	Qualitative: focus group discussion
Martin 1997 USA [46]	Clinical osteoporosis (BMD > T score -2.5 with a history of fragility fracture)	465	Source of participants unspecified (222 participants met definition of clinical osteoporosis and 243 were defined as non-	78% of osteoporotic women aged 70 or older 100% female	To quantify the effect of osteoporosis on quality of life of all women	Quantitative: questionnaires

			osteoporotic			
Mauck 2002 USA [47]	Low impact fracture (i.e. fall from standing height or less).	21	Consecutive postmenopausal women >50 years who were hospitalized with a low-impact acute proximal femur fracture in May - August 2000, identified from the computerised admission records.	Mean age 81 (SD7) 100% female	To explore the process a woman negotiates when deciding to accept pharmacologic treatment for osteoporosis after a hip fracture.	Quantitative: questionnaires
Mazor 2010 USA [48]	Osteoporosis (BMD < T score -2.5)	36	A multispeciality group practice in Massachusetts.	Age range > 65 years 100% female	To examine individuals' beliefs and experiences related to osteoporosis and treatment.	Qualitative: phone interviews
McKenna 2008 UK [49]	Diagnosed with osteoporosis	21	Patients recruited through National Osteoporosis Society	Age range 43-82 years 100% female	To compare the experiences of osteoporotic Caucasian women and South Asian women during	Qualitative: interviews

	(criteria unspecified)		support groups, osteoporosis exercises classes and South Asian community centres		their primary care physician consultations.	
Payer 2009 Slovakia [50]	Women with BMD diagnosed osteoporosis (criteria unspecified).	2035	Participants recruited voluntarily for bisphosphonate treatment	Mean age 64 years 100% female	The aim of this VIVA II questionnaire-based study was to analysis the reasons for preferring once monthly bisphosphonates in patients with post-menopausal osteoporosis as a follow up to the published VIVA study.	Quantitative: questionnaires
Richards 2007 UK [51]	Osteoporosis status not determined.	2485	Population-based healthy twin volunteers, > 55 years	Mean age 64.5 (SD 6.4) 90.3% female	To discern which therapeutic attributes would be most preferred by a population representative of the age and sex distribution of patients with osteoporosis	Quantitative: questionnaires
Ringe 2006	No definition of	164	Postmenopausal women aged >55yo	Mean age 69 (SD 8.8)	To evaluate whether the intake instructions and packaging of the	Quantitative: semi-

Germany [67]	osteoporosis, half of the participants selected as current bisphosphonate users		recruited from Germany or UK. Source of participants otherwise unspecified.	100% female	new combination packaging with the once-weekly bisphosphonate risedronic acid and once-daily calcium tablets were better understood and preferred by postmenopausal women than if these women received separate packs of once-weekly bisphosphonate and calcium tablets.	structured questionnaires
Rizzoli 2010 USA [52]	Post menopausal osteoporosis diagnosed by a physician and were currently or in the past 2 years prescribed	844 patients and 837 physicians	Source of participants and recruitment not specified.	Age range unspecified (post-menopausal women) 100% female	To investigate gaps between physician and patient knowledge on osteoporosis, understand barriers to patient adherence and improve communication	Quantitative: telephone interviews

	medications					
Rothmann 2014 Denmark [53]	Women both with and without osteoporosis (DXA BMD T score <-2.5.)	31	Purposive sampling of participants from the ROSE study in Southern Denmark	Age range 65 – 80 100% female	To investigate women's perspectives and experiences with screening for osteoporosis.	Qualitative: focus group discussions
Sale 2010 Canada [54]	Patients > 65 years old, with or without a history of osteoporosis treatment, who had a fragility fracture in the last 5 years and deemed high risk for future fracture	21	Purposive sampling of patients identified from a fracture clinic osteoporosis screening program at an urban teaching hospital	Age range 65 – 88 71% female	To examine patients' experiences with the decision to take osteoporosis medication after they sustained a fracture	Qualitative: interviews

Sale 2014 Canada [55]	Patients >50 years, who had a fragility fracture (WHO definition)	25	Purposive sampling of patients presenting to a teaching hospital who experienced a fragility fracture and were candidates for fracture risk assessment.	Age range 50-79 88% female	To examine patients' experiences regarding BMD testing and bone health treatment after being screened through Ontario's Fracture Clinic Screening Program	Qualitative: interviews
Sale 2014 Canada [57]	Patients with osteoporosis-related fractures, but definition of osteoporosis not defined	25	Urban fracture clinic	Age range 50-79 88% female	To examine patients' self-management of bone health and fracture risk, particularly behaviours other than medication use and seeking diagnostic testing.	Qualitative: interviews
Sale 2014 Canada [56]	Patients who had a fragility fracture at > 50	28	Advertisement in a patient group newsletter	Age range 51 – 89 93% female	To examine experiences and behaviours with bone health management post-fracture among	Qualitative: telephone interviews

	years and were not taking osteoporosis pharmacotherapy at the time of the fracture				members of a national osteoporosis patient group	.
Sale 2015 Canada [35]	Patients who had a fragility fracture at >50 years and were not taking osteoporosis pharmacotherapy at the time of the fracture	28	Advertisement in a patient group newsletter	Age range 51 – 89 93% female	To examine messages perceived by members of an osteoporosis patient group from various healthcare providers regarding bone health	Qualitative: telephone interviews
Saltman 2006 Australia [58]	3 participant categories were chosen: (a) patients	1096	Patients recruited by general practitioners (110 primary care physicians from	Mean age of patients with preventatble condition 74.7,	To explore whether various models that have described patient beliefs and motivations for medication taking applied to	Quantitative: questionnaires

	diagnosed with a preventable condition ie osteoporotic fracture, taking bisphosphonates), (b) patients with other chronic conditions and (c) acute or no conditions		research network databases held at the University of Sydney each recruited 10 patients)	mean age of patients with chronic illness 71.3, mean age of patients with acute/no illness 69.2 100% female	patient preferences and decision making across a range of patients with different types of conditions and varying experiences of medication frequencies, and whether there were differences in characteristics between these groups	
Schousboe 2011 USA [59]	Patients with a prescription for an oral bisphosphonates	686	Patients recruited after reviewing the electronic medication record of Park Nicollet Clinic and who had a clinic visit within 6 months	Mean age 66.3 (SD 10.1) 94% female	To estimate the associations of patients' perceived need of medication for fracture prevention with objective indicators of fracture risk, patients' concerns about medications and the quality of the patient –physician	Quantitative: surveys

			of the mailing date of the survey		relationship	
Scoville 2011 USA [60]	Postmenopausal women aged ≥ 50 years with osteopenia or osteoporosis and not already taking bisphosphonates or other prescription medications	18	10 academic primary care sites partaking in Osteoporosis Choice (randomized trial of a decision aid)	Patients mean age 70.6 (SD 9.4) 100% female patients	To determine the reasons women present when expressing hesitation about initiation of bisphosphonates during primary care consultations with clinics and how these clinicians react by studying video recordings of these consultations	Qualitative: video recordings of encounters
Turbi 2004 Spain [61]	Postmenopausal women >55 years of age and at risk for osteoporotic	909	Open label, prospective, observational, nonrandomized study conducted at	Mean age 64.4 (SD 6.9) 100% female	To assess the compliance of postmenopausal women at risk for osteoporotic fractures who were treated with raloxifene vs alendronate during a 12 month	Quantitative: questionnaires

	fractures (physician diagnosed)		154 centres across Spain.		observation period in a routine clinical setting.	
Weiss 2005 Israel [63]	Postmenopausal women, treated with alendronate daily for at least 1 month within the preceding year.	3438	Medical providers from 14 hospital and 150 primary care community clinics recruited subjects.	Mean age 66.7 (SD 8.9) 100% female	To measure compliance, convenience, tolerance and relative preference of alendronate oral weekly treatment among postmenopausal women with osteoporosis and physician satisfaction compared with previous treatment with alendronate oral daily.	Quantitative: questionnaires
Weiss 2007 USA [64]	Patients with a history of osteoporosis or at risk of osteoporosis (unspecified definition)	999	Women were surveyed via the Internet as part of the National Health and Wellness Survey	Mean age 65.1 (SD8.2) 100% female	To assess patient preferences for 2 osteoporosis medications	Quantitative: surveys

Yood 2008 USA [65]	Osteoporosis defined as BMD T score < -2.5.	236	A multispecialty practice.	Age 35-33: 1.7%, 45-54: 10.6%, 55-64: 25.4%, 65-74: 28.4%, >75: 33.9% 100% female	To evaluate the influence of patient characteristics, perceptions, knowledge and beliefs about osteoporosis on the decision to initiate osteoporotic treatment	Quantitative: questionnaires
Yu 2015 USA [34]	Osteoporosis defined as a diagnostic ICD code for osteoporosis and evidence of BMD test	430	Patients identified from Optum Research Database and a cross-sectional mail survey was conducted	Mean age 61 100% female	To examine patients' reasons for not initiating osteoporosis treatment among women with osteoporosis	Quantitative: surveys
Zanchetta 2005 Argentina [66]	Postmenopausal women who had received prescription	419	Patients identified from the Metabolic Research Institute database	Mean age 61.4 (SD 7.4) 100% female	To assess the raloxifene compliance and continuance rates and adverse effects over 24 months in clinical practice	Quantitative: telephone interviews

	for raloxifene and had undergone BMD measurement					

Table 2. Patients' perceived need of healthcare providers for osteoporosis

AUTHOR, YEAR	RESULTS
Patient preference for consulting medical practitioners and their role	
Feldstein 2008 [38]	• Patients advocated for standardized protocols for integrating and involving specialists in the management of osteoporosis at the time of fracture. • Most patients thought that specialists should provide basic education in osteoporosis and initiate screening or treatment, with follow-up by a primary care provider or care manager
Hansen 2014 [41]	• Patients expect a thorough examination and informative consultation and clarity of diagnosis
Iversen, 2011 [43]	• Patients believed and trusted specialists such as endocrinologists and rheumatologists more than their primary care physician regarding osteoporosis management.
Lau, 2008 [45]	• Patients found follow up from health care providers for support and monitoring for medications very useful for improving adherence
Mazor 2010 [48]	• Many women relied on their physicians' recommendation in deciding whether to take osteoporosis medications
McKenna, 2008 [49]	• Patients preferred attending consultations, expecting primary care physician dialogue on osteoporosis
Sale 2014 [56]	• Patients believe the role of the doctor in their bone health was to prescribe medication that they requested, to do other routine activities such as annual exams and facilitate access to tests and provide current information

Sale, 2015[35]	• Patients were satisfied with the care they received from specialists with many patients reporting that their specialists were more interested in their bone health than their primary care provider. • Specialists were perceived to be more knowledgeable about osteoporosis, and they took more time to discuss their bone.
Desirable characteristics of the medical practitioner	
Besser 2012 [36]	• Patients wanted to be more involved with decisions related to treatment
Hansen 2014 [41]	• Patients wanted their osteoporosis to be taken seriously by their physician, which promoted a feeling of care and trust • A patient described how she felt taken seriously when her primary care physician referred to a specialist clinic for osteoporosis treatment
Lau, 2008 [45]	• Patients found follow up from health care providers for support and monitoring for medications very useful for improving adherence • Patients wanted to be able to discuss their medication problems with their physicians • Patients wanted a non-judgmental service from their doctors
Rizzoli, 2010 [52]	• Patients found it helpful to have more frequent contact with their physicians regarding osteoporosis
Dissatisfaction with, or concerns about, medical and non-medical practitioners	
Besser 2012 [36]	• Patients perceived lack of time during consultation, poor communication, lack of continuity of care as barriers to a good relationship with their doctor

Iversen, 2011 [43]	• Patients felt their health visits were not long enough to be able to discuss all their questions with their doctor. They also felt they were unable to bring up medication issues as their physicians were very rushed
Mazor 2010 [48]	• Some women expressed distrust and felt that doctors were too quick to recommend prescription medication
Martin, 1997 [46]	• Patients felt they had lack of definitive answers from their physician regarding osteoporosis
McKenna, 2008 [49]	• Patients were disappointed that consultations had a strong focus on medication and wanted to discuss other treatment options
Sale, 2015 [35]	• Patients perceived that their primary care providers were not interested in their bone health, and were dismissive of their concerns about osteoporosis. They also reported that the recommendations from different healthcare providers appeared to be inconsistent.
Preference for other healthcare providers	
Sale, 2015 [35]	• The messages received from other healthcare providers such as nutritionists, physiotherapists and chiropractors were perceived as sporadic, inconsistent and not forthcoming.

Table 3: Patients' perceived needs of pharmacotherapy for bone health and osteoporosis

AUTHOR, YEAR	RESULTS
Preference for medications and role of medications	
Besser 2012 [36]	.• Half of the patients said medication use in general was positive
Bogoch 2008 [37]	.• More than 85% of patients stated they would take medication for osteoporosis if their physician recommended such treatment
Fraenkel 2006 [39]	• Patients preferred bisphosphonates over hip protectors however older adults preferred to avoid taking prescription drugs for most health problems were more likely to prefer hip protectors
Lau 2008 [45]	.• Improvement in BMD, not having a fracture and having a quicker recovery after a fall positively reinforced persistence in taking osteoporosis medications .• Some patients believed that lifestyle modifications would be enough to prevent osteoporosis and that medications should be used as a last resort
Mauck 2002 [47]	.• Most women (62%) who were admitted to a tertiary hospital were either unaware of osteoporosis or had never considered pharmacologic treatment .• Previous BMD evaluation and a diagnosis of osteoporosis were associated with patients considering or currently taking medication
Mazor 2010 [48]	.• Some women viewed osteoporosis as a common consequence of aging and believed that medication was therefore not needed or not likely to be of benefit .• Some women expressed confidence in the effectiveness of prescription osteoporosis medications and thought that it

	may be helpful to eliminate their symptoms, help them avoid further decline in health, replace something that they cannot obtain through diet alone • Some patients seemed confused about medications, thinking that it would reduce pain • Some women reported that they did not like medications and would avoid whenever possible • For some women it is seen as the last resort, only when calcium supplements and exercise had failed • A diagnosis of osteoporosis seemed to lead directly to the perception that medications were needed • Knowledge of others' experiences also affected views on medication • Patients have a preference for using lifestyle changes rather than prescription medications for osteoporosis treatment
Sale 2010 [54]	• One participant considered his bisphosphonate to be a minor medication, just more like supplements • Participants were more likely to take bisphosphonates if they had a good relationship with their health care provider or trusted their doctor • Some patients perceive the benefits of bisphosphonates to include keeping the bone from weakening, providing extra strength for the bone, preventing further bone loss or improving the bone density • Some patients did not understand what the medications were for • One patient described being convinced to take medications because her physician gave a detailed explanation of the condition and medication and she felt confident to take the medications
Sale 2014 [56]	• Some participants describe requesting prescriptions for anti-resorptive medications • Patients who were not taking medications gave a variety of reasons including refusal to initiate the first

	prescription, refusal to continue the prescription, deciding to take a drug holiday, wanting to try non-pharmacological strategies
Schousboe 2011 [59]	• Patients' belief in their susceptibility to and severity of fractures and trust that the prescribing physician is competent and willing to consider their interests are associated with the patients' perceived need for medications
Turbi 2004 [61]	• More patients reported being satisfied with raloxifene compared with alendronate
Yood 2008 [65]	• Patients who have been told they had osteoporosis were more likely to start prescription medications than those who had not been told they had osteoporosis • Belief in medication effectiveness was associated with initiation of medications
Concerns about medications	
Besser 2012 [36]	• Half of the patients listed various concerns about medications including side effects, harmfulness, over prescribing, addiction, suspicion of pharmaceutical companies, dislike of chemicals, drug interactions and overdosing • Many participants expressed concerns about media reports of the link between bisphosphonates and oesophageal cancer
Hansen 2014 [41]	• The comprehensive package leaflet in the medication package and possible side effects caused worries and anxiety about taking medications
Hiligsmann 2014 [42]	• Patients disliked being at risk of gastrointestinal disorders more than being at risk of skin reactions or flu-like symptoms
Iversen, 2011 [43]	• Patients expressed uncertainty about how to take their medications • Side effects of medications were a primary reason for lack of adherence

	.• Method of medication administration and instructions were difficult for patients to remember
Lau 2008 [45]	.• Patients were unwilling to take a medication if they heard that a family member or friend had a negative experience or if they heard negative publicity about the medication in the media .• Some patients did not like to idea of taking any medications because they viewed medications as artificial and thought they had unpredictable effects. • Fear of breast cancer or cardiovascular events from hormone replacement therapy dominant patients' risk benefit assessments more than fear of other adverse effects, however, patients were willing to take hormone replacement therapy if they perceived their personal risk of these serious adverse events to be low
Mazor 2010 [48]	.• Some women expressed serious concerns about medications generally and fear of side effects in particular .• Some declined medications due to their concerns about side effects .• Some women discontinued medications after hearing reports of side effects through the media and other sources, even if they had not personally experiences side effects .• The administration of some medications (eg sitting upright) was interpreted by some patients as evidence that the medication was dangerous
Rothmann 2014 [53]	.• A patient did not want treatment as she had a first hand experience of a serious side effect (osteonecrosis of the jaw) in a close relative Patients were concerned about side-effects of taking a medication for a condition that otherwise was asymptomatic
Sale 2010 [54]	.• Some participants described concerns with bisphosphonates regarding adverse effects (wanting to see their dentist before starting treatment, history of multiple allergies and concern with further medications)

	Some patients were "turned off" medications by their physicians attitude
Scoville 2011 [60]	• Some reasons patients do not accept treatment include concern about side effects, history of adverse effects, distrust of medications, history of family member with no osteoporosis complications, good health without other treatments, perceived low value of potential benefits (too old to benefit, limited knowledge of osteoporosis, medications will not produce benefit)
Yood 2008 [65]	• Patients that had more distrust of medications and concern about side effects were more likely to not initiate medications
Yu 2015[34]	• The primary reasons for not initiating osteoporosis medication were concern over side effects (77.3%), medication costs (34.1%) and pre-existing gastrointestinal concerns (25%).
Zanchetta 2004 [66]	• Patients' reasons for not starting treatment for raloxifene included fear of thrombolytic events, lack of interest in starting treatment, other physicians' advice, family problems, dissatisfaction with the prescribing physician, treatment cost, health problems unrelated to osteoporosis, mistrust in the prescription, advice from family and friends, fear of breast cancer, belief that raloxifene is hormonal and polypharamcy.
Preferable therapeutic attributes of medications	
Gold 2006 [40]	• Once patients were informed of the differences in fracture efficacy between the 2 therapies, more patients preferred weekly therapy over monthly therapy
Hiligsmann 2014 [42]	• Patients preferred either an oral monthly tablet or 6 monthly subcutaneous injection above weekly oral tablets, 3-month subcutaneously or yearly intravenous injections
Keen 2006 [44]	• Patients preferred weekly bisphosphonate therapy to monthly

	• In the UK, patients aged 55-59 and those over 70 preferred weekly compared to women in their 60s that preferred monthly • Patients preferred weekly therapy due to perceived efficacy, dosing and convenience
Lau 2008 [45]	• Patients who found rearranging their daily routines difficult preferred the once-daily dosing option of bisphosphonates • Those patients who had successfully integrated taking medication into their daily routines found it easier to take medication every day rather than once weekly
Payer 2009 [50]	• Patients prefer once monthly dosing due to the convenience and simplicity of treatment and the need to take fewer pills. Other reasons that a minority of patients reported included fewer reminders of the disease and independence.
Richards 2007 [51]	• 45% of participants preferred daily medications, 20% preferred weekly and 30% preferred monthly medications • The least popular dosing frequency was twice per day • Participants that were not already taking anti-osteoporotic medications preferred daily therapy without having to remain fasting and upright after taking the medication compared with a weekly regime and monthly therapy • Subjects already taking non-weekly anti-osteoporotic medications preferred continuing with this routine • Subjects using weekly anti-osteoporotic therapy preferred weekly preparations
Ringe 2006 [67]	• Patients preferred combination packaging of bisphosphonates and calcium supplementation due to convenience, ease of understanding dosing instructions

Rizzoli 2010 [52]	• Patients desired osteoporosis treatments to not interact with other medications, have fewer side effects, require less frequent dosing, be easier to take and affect their regular routine less and have a less complicated dosing.
Saltman 2006 [58]	• Patients have a preference for weekly medication compared to monthly dosing
Weiss 2005 [63]	• 96% of women preferred alendronate weekly to the daily regime • Patients found weekly preparations more convenient • 77.6% of those who had previously stopped therapy with alendronate daily due to intolerance were willing to continue with weekly alendronate
Weiss 2007 [64]	• Effectiveness was ranked as the most important determinant of preference. Other less important reasons for a patient to prefer one drug over another included time on market, dosing procedure and dosing frequency.

Table 4: Patients' perceived needs of non-pharmacological management of osteoporosis

AUTHOR, YEAR	RESULTS
Calcium and vitamin D	
Bogoch 2008 [37]	• Patients generally agreed that regular exercise and calcium intake are beneficial in preventing osteoporosis
Feldstein 2008 [38]	• Patients expressed more willingness and comfort with taking supplements (calcium and vitamin D) than prescription medication for osteoporosis
Lau, 2008 [45]	• Calcium and vitamin D were perceived to be more "natural" than other osteoporosis medications and generally thought to be safe
Sale 2014 [57]	• Some participants watched their diet and/or taking supplements to improve their bone health • Patients exercise, have a healthy diet and take supplements to manage their bone health
Exercise therapy	
Bogoch 2008 [37]	• Patients generally agreed that regular exercise and calcium intake are beneficial in preventing osteoporosis
Sale 2014 [57]	• Patients exercise, have a healthy diet and take supplements to manage their bone health

Table 5: Patients' perceived needs of investigations for osteoporosis

AUTHOR, YEAR	RESULTS
Investigations for diagnosis	
Mazor 2010 [48]	• Patients noted the BMD test results at the time of diagnosis
Rothmann 2014 [53]	• Patients interpreted screening as an opportunity to get reassurance about bone status and take care of their own health.
Sale 2014 [56]	• Some participants reported persisting with the request to their family physician for a BMD test because of concern about their bones
Investigations for ongoing surveillance of bone health	
Besser 2012 [36]	• Patients wanted feedback from the DEXA scans to see if the medications were beneficial
Mazor 2010 [48]	• Patients thought the BMD results provided relevant feedback on the impact of their actions
Sale 2014 [56]	• Patients reported having to nag and follow up on their BMD test results

Author, Year	Criteria 1[1]	Criteria 2[2]	Criteria 3[3]	Criteria 4[4]	Criteria 5[5]	Criteria 6[6]	Criteria 7[7]	Criteria 8[8]	Criteria 9[9]	Criteria 10[10]
Bogoch, 2008 [37]	■	■		■			■		■	■
Fraenkel, 2006 [39]	■	■					■		■	■
Gold, 2006 [40]		■	■	■	■		■		■	■
Hiligsmann, 2014 [42]	■	■	■			■	■		■	■
Keen, 2006 [44]	■	■	■	■			■	■	■	■
Martin, 1997 [46]	■	■	■	■			■		■	■
Mauck, 2002 [47]	■		■	■			■		■	■
Payer, 2009 [50]	■	■	■	■		■	■		■	■
Richards, 2007 [51]		■		■		■	■		■	■
Ringe, 2006 [67]	■	■	■	■			■		■	■
Rizzoli, 2010 [52]	■	■	■	■			■		■	■
Saltman, 2006 [58]			■	■		■	■		■	■
Schousboe, 2011 [59]	■	■	■	■			■		■	■
Turbi, 2004 [61]	■	■	■				■		■	■
Weiss, 2005 [63]			■				■		■	■
Weiss, 2007 [64]		■	■	■		■	■		■	■
Yood, 2008 [65]	■	■	■	■			■		■	■
Yu, 2015 [34]		■	■	■			■		■	■
Zanchetta, 2005 [66]	■	■	■	■			■		■	■
Legend:		Yes		■	No					

Figure 1. Quality assessment of quantitative studies

[1]Criteria 1:Was the study's target population a close representation of the national population in relation to relevant variables?

[2]Criteria 2: Was the sampling frame a true or close representation of the target population?

[3]Criteria 3: Was some form of random selection used to select the sample OR was a census taken?

[4]Criteria 4: Was the likelihood of nonresponse bias minimal?

[5]Criteria 5: Were data collected directly from the subjects?

[6]Criteria 6: Was an acceptable case definition used in the study?

[7]Criteria 7: Was the study instrument that measured the parameter of interest shown to have validity and reliability?

[8]Criteria 8: Was the same mode of data collection used for all subjects?

[9]Criteria 9: Was the length of the shortest prevalence period for the parameter of interest appropriate?

[10]Criteria 10: Were the numerator(s) and denominator(s) for the parameter of interest appropriate?

Author, Year	CASP 1[1]	CASP 2[2]	CASP 3[3]	CASP 4[4]	CASP 5[5]	CASP 6[6]	CASP 7[7]	CASP 8[8]	CASP 9[9]	CASP 10[10]
Besser, 2012 [36]										
Feldstein, 2008 [38]										
Hansen, 2014 [41]										
Iversen, 2011 [43]										
Lau, 2008 [45]										
Mazor, 2010 [48]										
McKenna, 2008 [49]										
Rothmann, 2014 [53]										
Sale, 2010 [54]										
Sale, 2014 [57]										
Sale, 2014 [55]										
Sale, 2014 [56]										
Sale, 2015[35]										
Scoville, 2011 [60]										
Legend		Yes		No		Can't tell				

Figure 2. Quality assessment of qualitative studies

[1]CASP 1: Was there a clear statement of the aims of the research

[2]CASP 2: Is a qualitative methodology appropriate?

[3]CASP 3:Was the research design appropriate to address the aims of the research?

[4]CASP 4: Was the recruitment strategy appropriate to the aims of the research?

[5]CASP 5: Was the data collected in a way that addressed the research issue?

[6]CASP 6: Has the relationship between researcher and participants been adequately considered?

[7]CASP 7: Have ethical issues been taken into consideration?

[8]CASP 8: Was the data analysis sufficiently rigorous?

[9]CASP 9: Is there a clear statement of findings?

[10]CASP 10: How valuable is the research?

Supplementary Appendix – Search Strategy

Database: Ovid MEDLINE(R) 1946 to Present with Daily Update

Search Strategy:

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1 exp bone diseases/

2 exp bone density/

3 bone diseases, metabolic/ or bone demineralization, pathologic/ or osteoporosis/ or osteoporosis, postmenopausal/

4 osteopeni*.tw.

5 densitometry/ or absorptiometry, photon/

6 osteoporo*.tw.

7 dexa.tw.

8 densitometry.tw

9 bone mass.tw.

10 (bone* adj3 conten*).tw.

11 (bone* adj3 los*).tw.

12 (bone* adj3 densit*).tw.

13 osteopen*.tw.

14 (bone adj3 deminerali*).tw.

15 osteodystrophy.tw.

16 osteomalacia.tw.

17 4 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16

18 1 or 2 or 3 or 5

19 17 or 18

20 Bone Neoplasms/

21 19 not 20

Database: Ovid MEDLINE(R) 1946 to Present with Daily Update

Search Strategy:

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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 (

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