

## Men's perceptions of living with osteoporosis: a systematic review of qualitative studies

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### ABSTRACT

**Background:** One in five men will experience an osteoporosis-related fracture in their lifetime. However, osteoporosis is widely perceived as a women's disease and few studies focus specifically on men. Our objective was to identify qualitative evidence to understand men's perceptions of osteoporosis and fracture.

**Methods:** We conducted a systematic review following standardized guidelines. We identified qualitative studies that included men aged 18 years and over using the terms: osteoporosis, fragility or low-trauma fracture, bone health; and perceptions or experiences with osteoporosis and fractures. We appraised the quality of data and used a meta-aggregative approach to synthesize findings.

**Results:** We identified four publications, based on three studies (n = 61 participants); one of the publications was a secondary analysis. The following themes were developed from the literature: (1) perceived healthcare gap for men; (2) strong focus on women, with a need for support from spouses and health professionals; and (3) three general responses to men's osteoporosis self-management: limiting lifestyle, minimizing importance of diagnosis, and risk taking.

**Conclusions:** The most striking finding from this review was the lack of available qualitative evidence. However, it emerged that the present focus of osteoporosis as a women's disease may influence how men develop self-management strategies. These data highlight the need to include men in future osteoporosis health-related conversations and interventions.

**Systematic review registration:** CRD42018093999.

### Introduction

Older adults are at risk of low-trauma (fragility) fractures: women are more likely to fracture, but men may have worse outcomes after fracture (Cawthon, 2011); mortality for men following hip fracture is between two and three times that in women (Farford et al., 2015). Low-trauma fractures indicate lower bone mass (osteoporosis) (Jarvinen et al., 2008) and they often result from falls from a standing height or less. Although women have an increased risk for low-trauma fracture, there is no difference between men's and women's risk for subsequent fracture (Center et al., 2007). However, osteoporosis is frequently considered a "women's disease" (Farford et al., 2015). There are very low rates of investigation of men's bone health after low-trauma fracture (Feldstein et al., 2005). Further, men may not adhere to pharmacological therapy for bone health (Mikyas et al., 2014), with potentially harmful consequences. The costs are significant at a personal and

societal level for both women and men (Tarride et al., 2012). Reducing fall risk and managing bone health after fracture (secondary prevention) is essential (Binkley et al., 2017).

To address this potential care gap, and develop person- or patient-centered care plans, it is important to understand men's needs, experiences and perceptions of bone health and low-trauma fractures. The cornerstone of patient-centered care is to involve people in their health and medical management – to develop meaningful and important outcomes. Based on a systematic review, Kitson and colleagues identified three overarching components of patient-centered care: engagement of patients, relationship between patients and health professionals and context of care delivery (Kitson et al., 2013). Specifically, they highlight the need to develop health management based on patients' needs and preferences (Kitson et al., 2013). Given the lack of emphasis on men and osteoporosis or low-trauma fracture, development of patient-centered care may pose some challenges.

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To move forward in developing prevention and management strategies that are acceptable to men, the next step is to synthesize available evidence on men's perceptions of bone health and low-trauma fracture. Therefore, we conducted a systematic review following recommended guidelines (Moher et al., 2009) to synthesize available evidence. We only included qualitative evidence because we believed the methodology would provide an in-depth reflection of men's perceptions of a diagnosis of osteoporosis and fracture. The goal of this work is to provide a summary of men's perceptions of bone health as a foundation for others to use in the process of testing and developing patient-centered interventions, in future.

## Methods

**Protocol and registration:** We conducted a systematic review following the guidelines for conducting and reporting as established by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (Moher et al., 2009). Prior to starting the process, we registered the title and methods on PROSPERO CRD42018093999.

**Systematic Review Team Members:** Our review team had representation from the academic and clinical communities. The multidisciplinary team included a clinical epidemiologist, nurse, occupational therapist, physiotherapist, trainee medical doctor and researchers. The senior author (MCA) has previously published systematic reviews and, specifically, within the bone health field; she was involved in all aspects of the study. Our team also included an occupational therapist (WBM) and clinical epidemiologist (JS) with expertise in qualitative methods.

**Eligibility criteria (Concepts):** We only included peer-reviewed, publications using qualitative methodology, and studies that represented the following concepts: **population:** men aged 18 years and older; **exposure:** osteoporosis, fragility or low-trauma fracture, bone health; and **outcomes:** perceptions of bone health/osteoporosis and fractures.

**Information sources and searches:** The senior author (MCA) developed the search strategy and the other co-authors reviewed it for completeness and comprehensiveness. We searched the following electronic databases for all years: Ageline, Anthropology Plus, Biomedical Reference Collection, Cumulative Index to Nursing and Allied Health Literature (CINAHL) Complete, Embase, Humanities and Social Sciences, Index Retrospective, MEDLINE (Ovid), PsycArticles, PsycINFO, and SportDiscus. Our last search was conducted on April 15, 2018. Fig. 1 is an example of the search strategy conducted in Medline. We also conducted a focused search in Google Scholar (allintitle) using the following key words: “men and osteoporosis” or “low-trauma” or “fragility fracture”. We uploaded identified citations to Covidence (Covidence systematic review software, Veritas Health Innovation, Melbourne, Australia) which removed duplicates and tracked information for creating the PRISMA flow diagram. For all studies included at the full text level, we conducted a forward citation search, and reviewed their reference lists. The senior author (MCA) screened reference lists and excluded any webpages, reviews, methods/outcome measures studies, or irrelevant references. We included literature from all years and in all languages.

**Study Selection (Screening, Level 1, Level 2):** The senior author (MCA) screened titles and abstracts of studies (Level 1), using Covidence. For Level 2 screening, two authors (AC) screened all studies and decided the final list of included studies.

**Data processing:** We extracted the following information for each included study: author, year, country, setting, population, type of interviews, analysis methods, and key findings. Our outcomes of interest were men's perceptions of living with osteoporosis and/or low-trauma/fragility fractures.

**Quality assessment:** We used the 10 questions from the Critical Appraisal Skills Programme Checklist (<https://casp-uk.net/wp-content/uploads/2018/03/CASP-Qualitative-Checklist-Download.pdf>) to

evaluate the quality of study methods employed in the individual studies. We chose this appraisal system to assess the rigor of study design and analysis. Two of three of the authors (MC, AC, MCA) independently adjudicated each study using Covidence. Following this, the authors met (either online or in person) to resolve any initial conflicts, and did not need an additional author to resolve differences. We did not exclude studies based on the results from the quality assessment.

**Synthesis of results:** We followed the Joanna Briggs methodology for synthesizing qualitative evidence known as the meta-aggregative approach (Lockwood et al., 2015). The first author (MC) extracted themes and quotes from all included studies. Following this, two authors (MC, MCA) reviewed quotes and then together sorted quotes into similar categories to develop synthesized findings (concept mapping). We included references and page numbers to direct quotes from included studies.

**Managing bias:** During the review process, team members strived to reduce bias via engaging two reviewers who independently adjudicated potential publications at Level 2, and assessed study quality. In addition, no author of an included publication assessed its quality. We considered how personal assumptions might influence interpretations.

## Results

Fig. 2 provides an overview of the study selection process. We identified 2223 citations across databases, including 72 citations from the EBSCO Databases, 1339 from Embase, two from Google Scholar and 810 from OVID Medline. We removed 481 citations (duplicates, reviews or animal studies). We reviewed at 1897 citations at Level 1 (Title and Abstract) and 21 full text publications at Level 2. There were only four publications (Nielsen et al., 2011; Sale et al., 2016; Solimeo, 2011; Solimeo et al., 2011) (based on three studies) which met the inclusion criteria for entry into the review. One of these publications was a secondary analysis (Sale et al., 2016). There were enough similarities between the publications to justify combining data for the synthesis.

**Participant characteristics:** Across the three studies, there were 61 men interviewed, with a mean age between 50 and 88 years. All men were community dwelling and diagnosed with osteoporosis and other chronic conditions. Over two-thirds of the men had previously sustained fracture (41/61). There was some variability noted for educational background, income, occupational status, marital status and living arrangements. More than half of the participants (47/61) lived with another person (e.g., spouse, partner or family member). Only one study (Sale et al., 2016) identified a participant with a same-sex partner. Only two studies reported information on income and education (Nielsen et al., 2011; Solimeo, 2011; Solimeo et al., 2011): In these studies, most participants were retired and self-reported financial security.

**Study characteristics:** The included studies employed qualitative methods, were published between 2011 and 2016, and aimed to explore men's perceptions, attitudes and behaviours of living with osteoporosis and or fracture. One study contributed data from two publications (Solimeo, 2011). In two of the studies, participants received formal education on osteoporosis (Nielsen et al., 2011; Sale et al., 2016). For example, in the study from Denmark, participants completed a 4-day osteoporosis education program (Nielsen et al., 2011). While in the Canadian study, participants received education and recommendations from a bone health coordinator prior to the study (Sale et al., 2016).

**Rigor of individual study methods:** Three authors (MC, AC, MCA) independently reviewed publications to examine study quality using the Critical Appraisal Skills Programme Checklist. Following comparison and discussion of scores, authors categorized most items as predominantly high quality (Supplementary Fig. 4a and 4b), providing confidence in the analysis and interpretation of their results. There were minor discrepancies in reporting of the methods between the two publications by Solimeo (Solimeo, 2011; Solimeo et al., 2011), but we

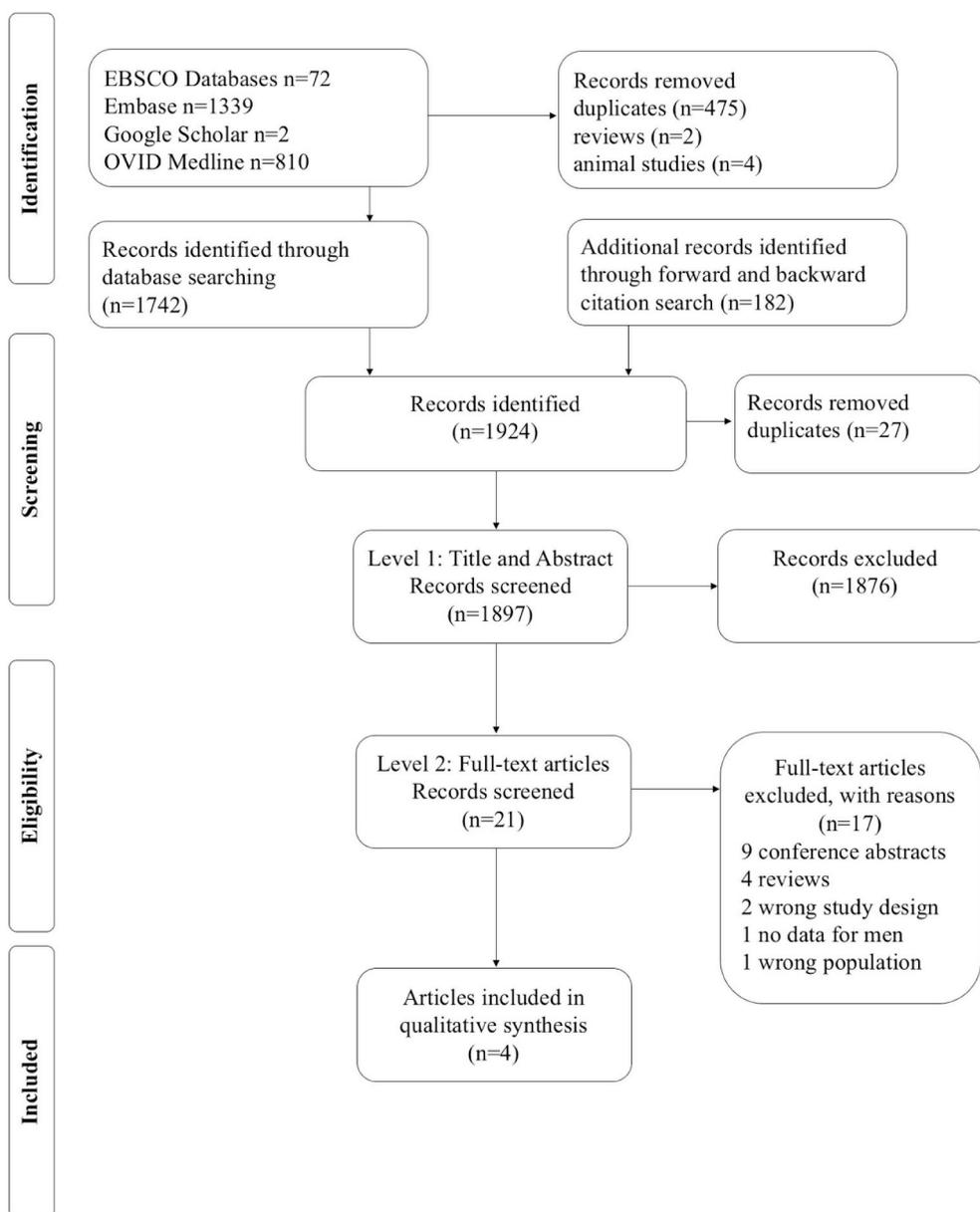


Fig. 1. Search strategy for Ovid Medline.

allocated a high score overall to this study.

**Synthesis of findings:** There were 72 quotes extracted from the four publications. We used meta-aggregation to synthesize findings of men's experience of osteoporosis (Fig. 3). Two authors (MC, MCA) discussed the credibility of the synthesized findings extracted from the data and found them to be unequivocal. There were three main synthesized findings generated within the context of a diagnosis of osteoporosis and or sustaining low-trauma fracture (Supplementary Table 1 and Fig. 5).

**Perceived lack of gender-based management of osteoporosis:** We identified 14 quotes from three of the four publications (Nielsen et al., 2011; Solimeo, 2011; Solimeo et al., 2011) that directly related to a gender-based gap in current clinical practice for osteoporosis. Men stated they were not adequately informed that osteoporosis could even affect men: "I think it is wrong that you are not informed that men can be diagnosed with osteoporosis" (Nielsen et al., 2011, page 6). This extended to participants' perceptions of their physicians' management of osteoporosis in men. "[My doctor] said that it was very unlikely that a guy would have it" (Solimeo, 2011, page 4). Frustration at the gap in

healthcare was illustrated by one man who said "I was mad at the doctors for not telling me [about the risk for osteoporosis] right away" (Solimeo et al., 2011, page 7). In particular, this frustration was related to not being told by the physician that osteoporosis could occur as an adverse effect of prescribed medication.

Many men disclosed genuine concern that there was a lack of clinical expertise on how to manage osteoporosis in men: "I hope that the male [osteoporosis] thing becomes more prominent in people's minds" (Solimeo, 2011, page 4). Men across studies acknowledged a lack of investigation into gender-specific osteoporosis management. One man in particular summed up the general feeling of dissatisfaction when he said; "The medication that I'm taking was developed for ladies" (Solimeo, 2011, page 4).

**A focus on women and their essential caregiving role:** A striking theme in the men's dialogue was the emphasis placed on women in the context of osteoporosis: there was an explicit mention of this connection in 21 of 72 quotes, across all included publications (Nielsen et al., 2011; Sale et al., 2016; Solimeo, 2011; Solimeo et al., 2011). Some men did not perceive the diagnosis as significant because they associated it

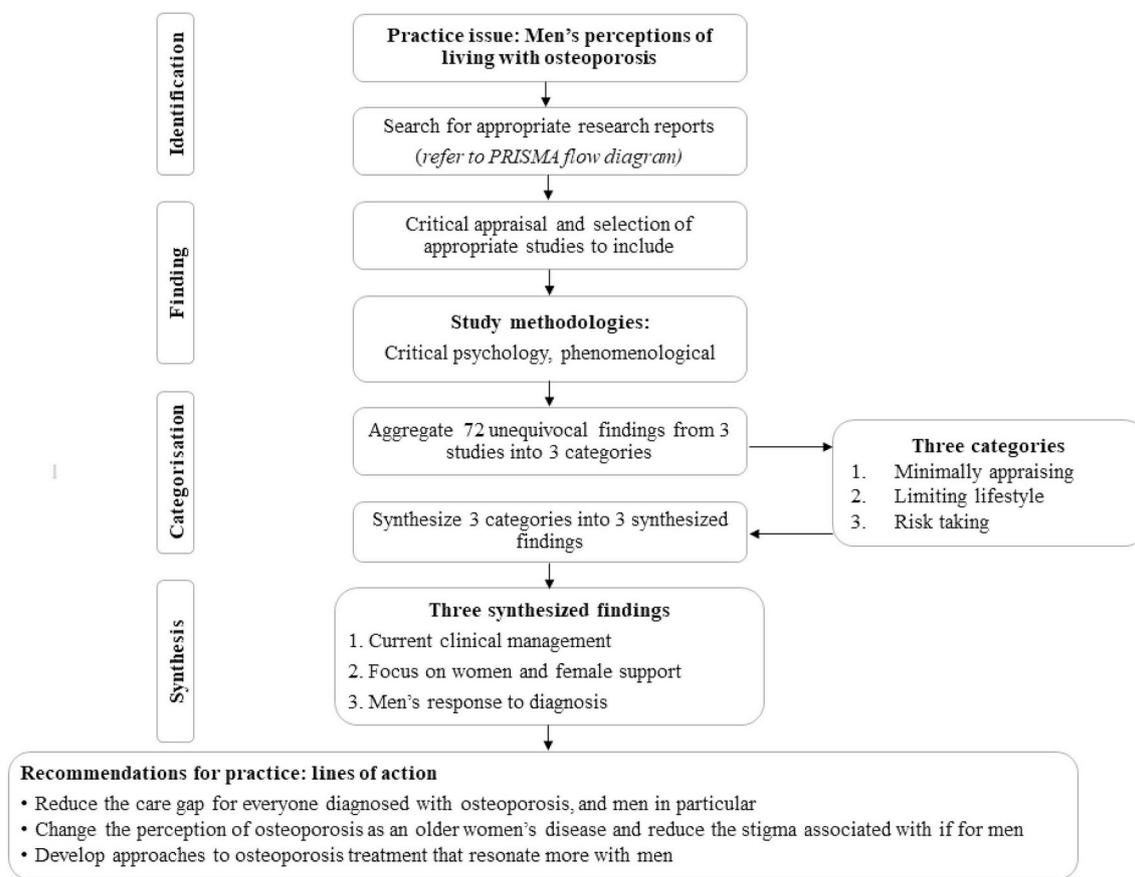


Fig. 2. Prisma flow diagram

with something women have; “You know grandmothers have it and live through it” (Solimeo, 2011, page 3). However other men perceived the diagnosis as a sentence which likened them to a “post-menopausal woman” (Solimeo, 2011, page 3). Even the fact that osteoporosis altered their physical appearance was something that was linked back to women. “I have been very embarrassed with men because of it, you know ... because I’m so bent over and I look so terrible. It’s not a manly kind of thing” (Solimeo et al., 2011, page 7).

Some participants found the constraints of gender stereotypes very

difficult; feeling trapped by their diagnosis that they believed forced them to assume a less manly persona. This was a challenge in some men’s personal lives, where they or partners found it difficult to come to terms with the diagnosis of osteoporosis. One participant remarked on the shame he felt in the company of his wife when he was not able to carry out traditional masculine tasks. “It bothers me so much that my wife has to carry our suitcases when we are travelling. I feel ashamed about not being able to help her, so I step over to the other footpath” (Nielsen et al., 2011, page 7). Many men acknowledged society’s ideals: “It’s just the

	Nielsen et al. 2011	Sale et al. 2016	Solimeo et al. 2011
Clear statement of research aims	+	+	?
Appropriate qualitative methodology	+	+	+
Appropriate research design	+	+	+
Appropriate recruitment strategy	+	+	+
Method of data collection addressed research issue	+	+	+
Relationship between researcher and participants adequately considered	+	+	?
Ethical issues taken into consideration	+	+	+
Data analysis sufficiently rigorous	+	+	+
Clear statement of findings	+	+	+
Value of the research	+	+	+

Fig. 3. The process of meta-aggregation.

way that society expects for a man – I mean, I don't expect for my wife to go out there and build a tree house for my grandkids." (Solimeo, 2011, page 5).

Furthermore, traditional gender roles were upheld in terms of the supporting role women played. Many men depended on support from women as a source of crucial encouragement and emotional backing in the setting of their osteoporosis diagnosis. Wives were described as the "driving force" behind bone health (Sale et al., 2016, page 3). On a practical level, spouses took charge of health promotion by removing loose carpets in the home and promoting calcium rich diets. In one study osteoporosis support groups were established, some of mixed gender, and some men only (Nielsen et al., 2011). Both were met with mixed emotions. Some men found that mixed gender groups enhanced the experience as women "bring us relevant information", whereas others believed that men feel more comfortable if it was "only men together" (Nielsen et al., 2011, page 7).

**Response to diagnosis of osteoporosis:** There were 25 of 72 quotes that directly highlighted that men placed low importance on the diagnosis of osteoporosis, and tended to adopt a risk taking mindset (Supplementary Figure 5). Some responded with an attitude of stubbornness and determination to continue to live their lives as they had been doing: "I believe it's true but I'm not going to live that way" (Sale et al., 2016, page 4). In particular, men emphasized the importance of maintaining a level of physical activity, especially when it came to outdoor work, such as mowing the lawn and carrying out heavy gardening tasks (Solimeo et al., 2011). Despite the risk attached to these activities, one man said, "If something has to be done I have to do it ... But grass – it's going to grow regardless so it's going to get cut regardless." (Solimeo et al., 2011, page 5).

At the other end of the spectrum were men who expressed concern over the diagnosis (Supplementary Figure 5). Two men described themselves as a "sissey" because of their osteoporosis (Nielsen et al., 2011, page 5), and another participant admitted that he lost his "self-esteem" (Sale et al., 2016). In contrast to a pattern of risk-taking behaviour, one man said he curtailed his physical activity in response to his diagnosis "The walks that I used to do were certainly much longer than the walks I do now" (Sale et al., 2016, page 4). We noted a number of quotes from men who limited their activities for fear of fractures.

In between these two perspectives, were the participants who had a muted response to the diagnosis of osteoporosis "I don't give them [bones] any thought" (Sale et al., 2016, page 4). Ignoring the gravity of the condition was the coping strategy of choice for one man "[I have] no perception at all [about my bone health]" (Sale et al., 2016, page 4). This group of men rejected the idea that having a fracture was of high importance: "I was in the Navy and if I had [the enemy] coming along side and wanting to shoot me, he wouldn't shoot me the second time ... I don't feel [at risk of another fracture]" (Sale et al., 2016, page 4). There was an active disinterest in anti-osteoporotic medication, illustrated clearly, when one man said, "It doesn't matter what I feel [about the fracture]. They told me to take it [medication] and I'm taking it" (Sale et al., 2016, page 4).

## Discussion

In this systematic review of men's perceptions of living with osteoporosis and fracture, we report a paucity of evidence from which to draw upon indicating a gap in clinical knowledge. However, consistent messages emerged from the literature. Osteoporosis care for men is far from exemplary and many current management strategies to support bone health have not been developed or tested with men. In addition, the scarcity of support for men living with osteoporosis may have negative repercussions, beyond the diagnosis. This may lead to challenges for men's sense of identity. Undoubtedly, osteoporosis affects more women over the lifespan: regardless, there remains a need for gender-based management and resources for men at risk for low bone mass and or fracture.

*There is a need to reduce the care gap for everyone and men in particular*

There is a well-documented care gap across both genders in the identification and management of osteoporosis (Gennari and Bilezikian, 2007; Papaioannou et al., 2008). In Canada, less than 20% of people receive osteoporosis treatment after sustaining low-trauma fracture (Majumdar et al., 2017). This clinical inconsistency in osteoporosis care is particularly obvious for men; what we know of the condition is almost entirely based on women (Diem et al., 2017). Both a diagnostic and therapeutic gap exists between knowledge and practice related to low-trauma fractures and osteoporosis in men over 50 years (Papaioannou et al., 2008). Even the prevalence of osteoporosis in men is poorly defined because there is confusion over which BMD measurements should be used for men's bone mineral density assessment (Gennari and Bilezikian, 2007).

Gender is a key social determinant of health, but men frequently do not seek help for health related conditions (Gough, 2006). The contemporary ideal of hegemonic masculinity has been noted as one of the main reasons for the health disparity we see between men and women (Evans et al., 2011). It has been shown that men perceive themselves as less susceptible to osteoporosis than their female counterparts (Johnson et al., 2008). Primary care physicians are responsible for the majority of osteoporosis medication prescriptions, yet management at this level is sub-optimal. High risk groups with a history of fracture often slip through the system without adherence to evidence-based prescribing practices (Desai et al., 2018). This suggests a call to action for primary healthcare physicians to take the lead with men's bone health.

*There is a need to change the perception of osteoporosis as an older women's disease and reduce the stigma associated with this diagnosis for men*

It is widely accepted that osteoporosis is perceived as a women's disease (Willson et al., 2015). In the included studies, support and encouragement from spouses/partners influenced men's reception and response to the diagnosis. Roberto and colleagues conducted a study on the influence of osteoporosis on the marital relationships of older couples, specifically focusing on women with osteoporosis (Roberto et al., 2016). This study noted that husbands were instrumental for providing support to their wives (Roberto et al., 2016). Similarly, in our review, wives of the men with osteoporosis played a crucial role in supporting their husbands both practically and emotionally.

Another recurring theme from this review was the assertion that osteoporosis was synonymous with older women, often making it difficult for men psychologically, physically, and socially. A qualitative study of men with breast cancer (France et al., 2000) revealed a host of similar issues, most notably associated with stigma, body image and the provision of information. The diagnosis of breast cancer in men has implications for the care and management of the condition, something we observed in this review in relation to osteoporosis. Although we recognize these are two very different health conditions, there may be similar challenges when a disease is traditionally associated with only one gender. There is also a discrepancy in the marketing of the disease in the media. Medical literature and brochures cater to women, making the condition less "men friendly." Because of this one-sided portrayal of osteoporosis, men may see the condition, or perhaps more crucially its prevention, as something that is irrelevant to them.

The diagnosis of osteoporosis as a challenge to a man's masculinity is something that came up repeatedly. Even the fact that current medication for osteoporosis was tested and developed on women only is something that men struggle with, as they try to navigate how that fits in with their identity. A related example of a gendered diagnosis is that of cardiovascular disease. With a long-standing history of being perceived as a "men's condition" many women went undiagnosed, leading to much poorer outcomes for women (Bird et al., 2018). Parallels exist between cardiovascular disease and osteoporosis: research and medical practice are primarily focused on just one gender.

### More work needs to be done to develop approaches to osteoporosis treatment that resonate with men

Consistent among the three studies was that men's response to their diagnosis was a varied one, and their self-identity in the context of their condition determined their reaction. Although we acknowledge that the men who participated in the osteoporosis educational program may have influenced their perceptions. In some cases the gravity of the diagnosis was undermined by the fact that it was perceived as a women's condition (Solimeo, 2011). This fits in with evidence suggesting that men tend to be less compliant with osteoporosis medication compared with women (Mikyias et al., 2014). Gough (2006) supports this idea with the assertion that masculinity is responsible for men's poor health and that to combat this, health services should adapt to reach men. That is, instead of fighting against the stereotype, we should leave conventional masculinities unchallenged (Gough, 2006).

Many men were adamant that they would not forgo their usual hobbies and activities. In some instances, men's outlook led to a perception that back pain, which may be an indicator of vertebral fracture, should be withstood rather than treated. Tolerance to pain without complaint may be a masculine trait (Courtenay, 2000). Many men continue to pursue exertional tasks in a need to justify their manliness, projecting these habits as badges of honor (Courtenay, 2000). This is in line with the theory that men perceive themselves only as masculine as their most recent portrayal of masculinity (Evans et al., 2011). The diagnosis of osteoporosis in men may also pose a challenge in some personal relationships as some women have reported struggling to come to terms with the perceived "feminine" diagnosis of their partners (Evans et al., 2011; Hurd Clarke et al., 2014).

In contrast, low bone density and fracture was a concern for a large proportion of men in the included studies; over two-thirds of the participants had sustained a fracture. This had an effect on their quality of life, causing them to alter their activity levels and some to give up previously enjoyed hobbies. Health related quality of life is significantly lower in people who experience fractures attributable to osteoporosis, in contrast to those with osteoporosis and no fracture (Papaioannou et al., 2009). Parallels to this were found in our review: men's perceptions of osteoporosis were influenced by previously sustained fractures. Those men who were limiting their daily activities, resulting in a reduced quality of life, had sustained a fracture. Unfortunately, reducing physical activity may result in prolonged periods of sedentary behaviour, which brings its own risks to health (Thorpe et al., 2011).

We note several limitations in this review, most predominantly was the lack of published studies: We could only identify three cohorts, including one that was a secondary analysis (Sale et al., 2016), with 61 men living with osteoporosis (with or without fracture). Due to the nature of this type of review, we were dependent on the interview guides, synthesis and interpretation of the original publication authors. These results are also limited to older, white, community-dwelling men. Although this may represent some of the target population, the external validity of the findings would be enhanced with more data, especially from men across the socioeconomic, ethnicity, and residence (e.g., nursing homes) spectrums. Another limitation to our review was only one author conducted Level 1 screening of citations. However, the author was experienced in the content area and in conducting systematic reviews.

In conclusion, a key finding of this systematic review was the obvious gap in evidence for men's perceptions of living with low bone mass, and its consequences. Regardless, we developed themes that emerged from the studies suggesting an interwoven relationship that may be contributing to how men identify with osteoporosis, and self-manage their condition. The themes suggest three main lines of action, including the need to: reduce the care gap for everyone, and men in particular; change the perception of osteoporosis as an older woman's disease and reduce the stigma associated with this diagnosis for men; and for more work on developing approaches to osteoporosis treatment

that resonate with men. To address these gaps, men and their perspectives are essential in the management of osteoporosis and low-trauma fractures. Education and awareness of osteoporosis in men is key in achieving exemplary care. This includes the education of health providers (e.g., primary care physicians, pharmacists and other community-based health providers) and society, in general. Given the number of men at midlife and older who have low bone mass and/or sustain a low-trauma fracture, it is important to develop a more gendered approach for osteoporosis management.

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### Conflict of interest

None to declare.

### Ethical approval

This is a systematic review, and ethical approval was not required.

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### Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.ijotn.2018.11.007>.

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