

1 **Expressed information needs of patients with osteoporosis and/or fragility fractures: a systematic review**

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16

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18

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24

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26

27 **Mini Abstract:**

28 This systematic review identified patients have unmet information needs about the nature of osteoporosis,
29 medication, self-management and follow-up. Clinician knowledge and attitudes appear to be of key importance
30 in determining whether these needs are met. Unmet information needs appear to have psychosocial
31 consequences and result in poor treatment adherence.

32

33 **Word count** 4754

34

1 **Abstract**

2 **Purpose:** Patient education is an integral component of the management of osteoporosis, yet patients are
3 dissatisfied with the information they receive and see this as an area of research priority. This study aimed to
4 describe and summarise the specific expressed information needs of patients in previously published [qualitative](#)
5 research.

6 **Methods:** Using terms relating to osteoporosis, fragility fracture and information needs, seven databases were
7 searched. Articles were screened using predefined inclusion and exclusion criteria. Full text articles selected for
8 inclusion underwent data extraction and were quality appraised. Findings were drawn together using narrative
9 synthesis.

10 **Results:** The search identified 11024 articles. Sixteen empirical studies were included in the review. Thematic
11 analysis revealed three overarching themes relating to: specific information needs, factors influencing whether
12 information needs are met, and the impact of unmet information needs. Specific information needs identified
13 included: the nature of osteoporosis/fracture risk; medication; self-management and understanding the role of
14 dual energy x-ray absorptiometry and follow-up. Perceived physician knowledge and attitudes; and the attitudes,
15 beliefs and behaviours of patients were important factors in influencing whether information needs were met, in
16 addition to contextual factors and the format of educational resources. Failure to elicit and address information
17 needs appears to be associated with poor treatment adherence, deterioration of the doctor-patient relationship
18 and important psychosocial consequences.

19 **Conclusion:** This is the first study to describe the information needs of patients with osteoporosis and fracture,
20 the impact of this information gap and possible solutions. Further research is needed to co-design and evaluate
21 educational interventions with patients.

1 **Introduction**

2 UK government policy places emphasis on providing patients with good quality health information, in order to
3 encourage patient participation in healthcare and ensure that patients have greater power, protection and choice
4 in key aspects of their care (1)]. As well as promoting patient centred care, this policy is an important driver in
5 the management of health resources, achieved through emphasis of the importance of self-management.
6 Especially in the context of an ageing population, and with increasing prevalence of long term conditions such
7 as osteoporosis, a strategy whereby patients accept more responsibility for managing their own conditions which
8 in turn will reduce or, thwart the increase in demand on healthcare resources.

9
10 Patient information is a key component of effective self-management (2)] and specifically in relation to
11 osteoporosis and fracture prevention, information and education interventions have been shown to improve
12 outcomes including health-directed behaviours and positive and active engagement in life, skill and technique
13 acquisition, and social integration and support (3)]. Patient education centres on the assumption that patients
14 who are better informed about their condition and management will be more likely to adopt positive health
15 behaviours, and will therefore improve, maintain, or slow deterioration of their health status (4)]. However, this
16 viewpoint of patient education does not acknowledge the role of patient opinions and choice and implies that
17 health professionals set the education agenda and define optimal health behaviours (5)].

18
19 Patients are often dissatisfied with the information they receive from health professionals. A recent national
20 survey of 1088 supporters of the National Osteoporosis Society (NOS) rated ‘easy access to information from
21 health professionals’ as the number one research priority for osteoporosis and fracture out of forty domains (6)].
22 The focus groups that preceded this survey emphasized the importance, yet the relative lack, of information
23 given by healthcare professionals early on in the participant’s pathway, e.g. at time of diagnosis, and in ongoing
24 consultations with primary care clinicians (7)].

25
26 To date, studies that have attempted educational needs assessment in osteoporosis have done so by
27 measuring patient knowledge and inferring educational unmet need based on inaccurate answers to
28 factual surveys (8-10)]. These surveys tell us nothing about what patients want to know. Furthermore,
29 Quantitative methods fail to capture the context which underlies the reported needs of patients; and
30 narrows our understanding given the deductive approach. Qualitative research methods facilitate the

Comment [AE1]: I think it is suggesting this statement be referenced – is the Superio-Cabuslay ref (4) to support both parts of this sentence?

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1 in depth understanding of the thoughts and perceptions that underlie and influence information needs
2 of patients, facilitating informed approaches to target unmet need.

3 ~~In order to further understand the nature of the research agenda relating to information needs (6);~~

4 ~~€The aim of this study was therefore to describe and summarise *patient expressed* information needs~~
5 ~~in previously published qualitative research, research, to better understand the nature of the research~~
6 ~~agenda relating to information needs of patients with osteoporosis and/or fractures (6) ~~in order to further refine~~~~
7 ~~research questions relating to patient information.~~

9 **Methods**

10 **Literature search:** The review was conducted based on a pre-established protocol (detailed eligibility criteria
11 and search strategy are presented in Table 1, and supplementary material). A systematic search for qualitative
12 studies on expressed information needs of patients with osteoporosis/fragility fracture was conducted in seven
13 databases; Medline, EMBASE, PsychINFO, Web of science, CINAHL, HMIC, AMED ~~from their inception~~
14 ~~until~~ July 2016, ~~and~~ ~~Grey~~ literatures were sought. De-duplication of citations and title screening were
15 completed by JJ and GR. Screening of abstracts against eligibility criteria and subsequent full text reviews were
16 independently completed by pairs of reviewers (GR and either ZP or OB). Disagreements regarding study
17 eligibility were resolved via discussion till consensus is achieved by the team.

18
19 **Quality assessment:** Eligible studies were independently appraised by pairs of reviewers (GR, AE and OB).
20 Two tools were used to support this. We chose the Hawker tool (11), as our main quality assessment tool
21 because it is designed for studies using different methods and can be used to give a quality score. This tool
22 includes nine domains (Title/abstract; Introduction/aims; methods/data; sampling; analysis; ethics/bias; results;
23 transferability; usefulness). However, we also used the Critical Appraisal Skills Programme tool for qualitative
24 research (12), to inform our scoring as this tool – divided into similar domains as the Hawker tool - provides
25 more detail about specific quality issues relating to qualitative research. using the Hawker tool for appraisal of
26 qualitative studies (11), and further informed by items in the Critical Appraisal Skills Programme tool for
27 qualitative research (12)]. For each study, individual items on the tool were given a score of either good, fair,
28 poor or very poor (4, 3, 2 or 1 points respectively)(11), giving a total score out of 36. Variation in scores was
29 resolved through discussion with a third reviewer (ZP) and final quality scores were agreed by consensus. No

Comment [AE2]: Zoe please can you add in how you did this in response to R2 point 6?

Comment [p3]: Jo/Yemi?

1 paper was excluded based on quality scores; it has been argued that excluding studies on the basis of quality
2 criteria may exclude insightful studies. However, study quality was considered during the synthesis stage.

Comment [p4]: Ref Campbell R, Pound P, Morgan M, Daker-White G, Britten N, Pill R, Yardley L, Pope C, Donovan J (2011) Evaluating meta-ethnography: systematic analysis and synthesis of qualitative research. Health Technol Assess 15(43):1-164

3
4 **Data extraction:** Using a customised data extraction form, information relating to author, title, date, country of
5 origin, research question, method, sample and setting, year of publication, author's findings and conclusions,
6 from each study, was extracted. Extracted data was checked for consistency and accuracy.

7
8 **Synthesis:** Extracted data was tabulated and a thematic analysis was conducted. Findings relevant to our review
9 objectives were grouped under the following headings:

- 10 • expressed information needs i.e. where patient participant(s) was/were described as wanting to know
11 more
- 12 • expressions of uncertainty i.e. where patient participant(s) was/were described as being confused or
13 unsure
- 14 • findings describing examples where information was given and was helpful
- 15 • ~~expressed participant expressions of uncertainty regarding about given information; inferred~~
16 information needs (i.e. where authors deduce a need based on tested or assumed knowledge rather than
17 patients expressing a need directly).
- 18 • Anything else of relevance to giving and receiving of information

19 ~~The latter (i.e., Inferred information needs)~~ ~~were~~ not included in subsequent stages of the analysis as it did
20 not relate to our research question. ~~We conducted~~ ~~When participants E~~ ~~expressed uncertainty about given~~
21 ~~information, this was interpreted as a patient expressed information need.~~ Thematic analysis on the data
22 extracted, manually. The first stage was initially descriptive – to identify a taxonomy or classification of the
23 types of information needs identified. We considered quality within each theme, ensuring that no theme was
24 reliant completely on papers with scores of poor/very poor. Subsequently ~~levels of analysis~~ were more
25 interpretative level of coding was applied to explore and determine explanations for initial findings. Next, we
26 revisited the original study findings to ensure our themes represented all the relevant findings. in order to ensure
27 that all findings from included studies were adequately considered and represented. And a higher level of
28 abstraction was achieved by grouping subthemes into higher level overarching themes. ~~F~~ Following an iterative
29 mapping process and team discussions (ZP, GR, OB), through which ~~a theoretical model~~ conceptual framework
30 was developed.

1

2 **Results**

3 11,007 unique citations were identified by the initial search and a further seventeen by reference and citation
4 checking. The review process and study flow is presented in Figure 1. Sixteen studies were included for data
5 extraction and quality appraisal.

6

7 **Summary of included studies**

8 The characteristics of the included studies are summarised in Table 2, including research question, country of
9 origin and methods. Eleven studies utilised single semi-structured interviews (13-23)] and focus groups were
10 used as method in the remainder (24-28)]. Eleven of the sixteen included studies recruited patients from
11 secondary care populations (13, 14, 17-19, 22-27)], with the rest recruiting from primary care (15, 20)],
12 community or mixed settings (16, 21, 28)]. Three studies included patients with specific fracture types (two hip
13 and one vertebral) (17, 21, 23)], and in these the research question and information needs related to the specific
14 fracture care in addition to general issues pertaining to osteoporosis (17, 21, 23)]. Seven studies were primarily
15 concerned with attitudes and perceptions regarding medication or supplements (13-15, 20, 26-28)], with the
16 others focused on experience of living with the condition more generally. Only three studies had research
17 questions that were directly related to information needs (18, 19, 21)]. One study aimed to explore knowledge
18 after an education programme; although this was not directly relevant to our research question the qualitative
19 approach used did elicit directly *expressed* information needs (25)]. For the remainder studies, only a small
20 proportion of the total findings relating to information needs were relevant to our research question and
21 extracted.

22

23 **Summary of findings relating to quality appraisal**

24 The findings related to quality appraisal are summarised in Table 3. Individual scores for quality appraisal by
25 authors GR, AE and OB were congruent in 115/144 (79.9%) domains. Nine studies were scored as 'fair' or
26 'good' in all domains (13-17, 19, 20, 24, 28)]. Studies scoring 'poor' or 'very poor' did so in domains relating to
27 sampling, ethics and bias, analysis, results, transferability and implications. The most common limitation of the
28 included studies was failure to adequately describe the characteristics of the participants. For example, age was
29 discussed regarding eligibility criteria, but the ages of included participants were not included (21, 25)].

1 Limitations of the sampling or recruitment also affected the transferability and implications of the findings
2 (25)].

3

4 **Main findings**

5 The main findings are summarised in Table 4. Of the sixteen included studies, 13 discussed directly expressed
6 information needs and 12 studies discussed uncertainties. Thematic analysis of the findings revealed three
7 overarching themes ~~as illustrated in Figure 2, and~~ discussed individually below, and displayed in the conceptual
8 framework in Figure 2.

9

10 ***Specific information needs:*** Information needs were illustrated in all of the studies. The needs related to some
11 or all of the following: the nature of osteoporosis and fracture risk; medication; self-management and/or the role
12 of dual-energy X-ray absorptiometry (DXA) and follow up.

13

14 ***The nature of osteoporosis and fracture risk:*** The relationship between osteoporosis and age was a topic of
15 uncertainty, causing some to question the need for medication for a condition that maybe considered normal for
16 age (19, 20)]. Doubt was expressed that osteoporosis was asymptomatic with participants in one study
17 attributing a range of symptoms to the condition including pain, rotting teeth and flaking nails (13)]. Findings
18 from a further focus group study suggested that participants felt musculoskeletal pain experienced on activity
19 was a signal of an imminent fracture (25)]. Participants sampled from a study of screening for osteoporosis
20 described uncertainty regarding communication of fracture risk, leading some to question the validity of the
21 assessment (20)]. The prognosis of osteoporosis, and the seriousness of osteoporosis was a cause of uncertainty,
22 which resulted in fear of the future (13, 23)]. In a similar vein, patients recovering from hip fracture wanted to
23 know in more detail what recovery would like and what the key ‘milestones’ would be (21)].

24

25 ***Medication:*** Uncertainty about the purpose of medication was described in several studies (13, 15, 27, 28)] and
26 half of the participants in the interviews reported in a study published in 2012 had not considered that
27 medication would reduce fracture risk (13)]. In one study, a participant described a perception that
28 bisphosphonates would reduce risk of falls (20)]. One study focused on views on medication, participants
29 described wanting to know more about the ‘pros’ of treatment (15)]. Information regarding medications was
30 described as too complex to understand (13)]. Participants wanted more information on how to take

1 bisphosphonates, (27, 28)] and in two studies, participants stated that they wanted to understand the reasons why
2 there were specific instructions on how to take bisphosphonate medication (13, 15)]. Men described wanting to
3 know what medication was specifically suitable for them (22)].

4
5 Sale et al. reported that some participants confused their bisphosphonate medication with their supplements
6 (25)]. Participants expressed a lack of guidance regarding recommended supplements (18)], and the correct
7 dose, explaining they were conflicted when choosing different sources of information to follow (25)].

8
9 *Self-management:* A recurrent theme across seven studies in patients with osteoporosis was the expressed view
10 that consultations contained too much of a focus on pharmacological interventions, with advice for other non-
11 pharmacological management e.g. diet and exercise being relatively neglected (13, 15-17, 21, 25, 28)]. In
12 particular, the aim of one study was to explore the level of perceived support for physical activity and
13 supplements given by participants' general practitioners (GPs) (16)]. Many participants in this study felt their
14 needs relating to self-management were better met by the NOS charity rather than within the DXA consultation
15 (16)]. Participants felt unsure with regards to the type and duration of activity they should be doing to help
16 osteoporosis generally (16)]. In terms of fracture recovery, patients with hip fracture described that
17 physiotherapists were good at explaining the purpose of exercises and which exercises to do (17)]. Patients
18 valued information on mobilisation and exercise programmes (21)] and particularly valued feedback on their
19 individual progress (17)]. In contrast, in a study of women's experiences of living with vertebral fractures,
20 participants did not feel they were given any advice on self-care, with the exception of pain relief and advice to
21 rest, which resulted in feelings of resentment and frustration (23)].

22
23 Dietary sources of calcium and vitamin D were another area of uncertainty for participants, explaining they were
24 unsure what to eat and whether dietary sources replaced their supplements (25)].

25
26 *Role of Bone Densitometry (DXA) and follow up:* In one study, some participants expressed confusion regarding
27 the purpose of bone mineral density (BMD) scanning, who it was for, and why only certain parts of the skeleton
28 were measured (25)]. This viewpoint was echoed in a study of outpatients from a secondary care clinic, where
29 participants described a need for a better understanding of DXA scans and more feedback on their results (13)].
30 In the interview study conducted by Salter et al., the lack of follow up was described, with a participant

1 describing the contrast between follow up for anti-hypertensive medication consisting of blood pressure checks
2 to ensure medication is effective, with the absence of follow up for bisphosphonates (20)]. The authors suggest
3 that specific medication follow up would increase confidence in medication (20)], which is supported by
4 findings in another study where participants expressed that follow up was needed to support persistence (28)].
5

6 ***Factors influencing whether information needs are met***

7 *Perceived attitudes and knowledge of healthcare professionals:* Many participants in the included studies
8 perceived their physicians felt osteoporosis should be accepted as part of normal ageing, and that they
9 physicians were uninterested in the condition in general (19, 23)]. In addition to lack of interest, some studies
10 reported the perception that their physicians had a poor knowledge of osteoporosis, in secondary (13)] and in
11 primary care (27)]. Related to this was the perception that primary care physicians underestimated the impact of
12 osteoporosis on their patient's quality of life, calling for suggestions that patients need to be more involved in
13 education programmes (16)]. Where knowledge was perceived to be poor, study participants described a lack of
14 confidence in their GP's advice, particularly relating to physical activity (16)]. In the study of patients with
15 vertebral fractures, participants described a feeling of not being taken seriously by their doctors, and a feeling
16 that osteoporosis and vertebral fractures were of low priority (23)].
17

18 *The attitudes, beliefs and behaviours of patients:* Information needs and information seeking behaviours differed
19 across the included studies in respect to self-efficacy, gender, age, and ethnicity. McKenna et al. explored South
20 Asian and Caucasian perceptions of support from their GP regarding non-pharmacological management (16)].
21 The authors reported that South Asian participants differed from Caucasian participants in their information
22 preferences in terms of tendency to consult the NOS, family members or whether they asked questions of their
23 GP (16)]. In addition, McKenna et al. consistently describe younger patients as being more proactive in seeking
24 information, with older patients being more resigned to having osteoporosis, feeling that their actions could not
25 change their prognosis (16)]. However, in this study, the definition of 'younger' is not clear: the study included
26 participants aged from 43-82 and quotes from two patients aged 74 and 76 are used to illustrate proactive
27 information seeking (16)].
28

29 Some studies reported that participants found it difficult to formulate questions (15)]. The need for a baseline
30 knowledge, in order to ask questions was also described; a participant's experience is described where she only

1 felt confident to ask her GP questions after visiting NOS support groups (16)]. The problem of lack of
2 confidence was also acknowledged in a study of experiences of people with hip fracture, with a carer suggesting
3 that patient advocates who can support patients in asking questions may be useful to overcome this (21)].
4

5 Very little information needs were directly expressed in the studies of men (22, 24)]. Male participants with
6 osteoporosis in one study described themselves as having ‘no problems’ despite reporting daily pain or restricted
7 activities; downplaying their symptoms or needs appeared to be part of a strategy to retain identity and a sense
8 of masculinity (24)]. Male participants in this study also described hesitation to consult their physician due to
9 fear of receiving an osteoporosis diagnosis and how this would impact employment (24)]. Efforts to consult or
10 ask questions were sometimes to meet the information needs of female partners, rather than their own.
11

12 *Context of information giving:* Information given at one point in time, e.g. in a busy fracture clinic, may be too
13 much to take in (25)] and therefore some participants with osteoporosis (although not all) expressed preference
14 for multiple opportunities to receive information through a series of consultations in primary care (16, 19)].
15 Similarly, a busy ward environment was described as not conducive for information giving, or asking questions
16 by patients with hip fracture, with the opportunity for multiple, repeated messages to be given during a stay in
17 an intermediate care unit post fracture being valued (17)]. This same study which investigated experiences of
18 people with hip fracture emphasised the importance of involving relatives and carers in post-fracture
19 information giving (17)].
20

21 *Types of information support:* Participants wanted both written and verbal information (17, 28)] and in a study
22 where participants were asked to draw diagrams to explain their own bone health, those interviewed felt the use
23 of more visual images would aid explanations in their routine healthcare (13)]. As has been previously
24 mentioned, ensuring that written information is understandable is key (13, 28)]. Whilst many study participants
25 already utilised other sources of information such as the NOS, participants in a Canadian study expressed a need
26 for more community sources of information (21)]. Two studies included participants that had attended support
27 groups or group education programmes: in these studies, participants who both had, or, had not attended these
28 spoke of the importance of having opportunities to meet people with similar experiences, of similar age and of
29 similar gender (19, 24)]. Others expressed an interest in being able to speak to people at a more advanced stage

1 of osteoporosis to gain an insight into ~~their-how their own outlook disease might progress~~, although one
2 participant felt this might be depressing (19)].

3

4 ***Impact of information needs being met/unmet***

5 *Initiation and adherence to treatment:* In two studies, the viewpoint that osteoporosis was normal for age was
6 cited as the principle reason for non-adherence with bisphosphonates; this viewpoint (that osteoporosis was
7 normal for age) was either reported as being directly expressed by a health professional (19) or the patient
8 participant's own reflection (20)]. In a focus group study by Sale et al., participants reported discontinuing
9 medication if it did not improve symptoms (25)].

10

11 DXA feedback aided medication adherence by providing evidence the medication was working (13)].
12 Uncertainties related to side effects and harm from the medication were reported by one participant who
13 described being anxious as to whether they were making the 'right choice' to take medication (14)].

14

15 *Doctor-patient relationship:* Maintaining a good doctor-patient relationship is reported as being integral to the
16 promotion of adherence with drug treatment, in a secondary care study (13)]. The same study discussed how
17 poor communication, and unmet information needs, may result in a negative perception of the doctor, and
18 resulting break-down in doctor-patient relations (13)]. The strongest narrative relating to the ~~doctor/clinician-~~
19 patient relationship was described in the study of women with vertebral fractures, although this study did not
20 present any participant quotations, nor did it make clear who the 'healthcare providers' were (23)]. The authors
21 report how participants described repeated feelings that their needs were not elicited by their healthcare
22 providers, that they felt not trusted by their doctors and that this resulted in a reluctance to then talk about their
23 situation or seek further help (23)]. ~~In this study, although participants were recruited in secondary care, the~~
24 ~~narrative centred around continuously asking for referral which suggested the 'healthcare providers' referred to~~
25 ~~were in primary care.~~

26

27 *Social and psychological consequences:* In a study of patients with hip fracture, those that were considered to
28 have unmet educational needs appeared to have an intensified fear of falling and to be 'emotionally
29 floundering', 'grasping to understand' and 'more likely to miscalculate risks' (17)]. In this study, tension in
30 relationships was also described when relatives had unmet information needs. Women with vertebral fractures

1 were described as having feelings of helplessness, underpinned by doubt and fear of an uncertain future (23)]. In
2 this study, fear of fracture and further pain influenced participant behaviour, leading to the avoidance of
3 activities, social withdrawal and feelings of loneliness (23)]. Marked anxiety and fear of fracture was also
4 described in the study by Hansen et al., underpinned by questions not being answered by the participant's GP
5 (14)]. The perception of osteoporosis as a female disease, reinforced by imagery on patient information leaflets
6 was associated with feelings of shame and embarrassment in men with the condition (24)]. The authors of two
7 included studies compare this degree of mortification to that experienced by men diagnosed with breast cancer
8 (22, 24)].

9

10 **Discussion**

11 This review aimed to understand the information needs of patients with osteoporosis and/ or fragility fractures in
12 order to refine research questions in this area, which is a priority for patients. The findings illustrate that one size
13 does not fit all with a wide range of needs and preferences regarding information, as might be expected.
14 However, the finding that core information needs prevail regarding the nature of osteoporosis, including the
15 relationship with ageing and pain, the purpose of drug treatment, and the nature of non-pharmacological
16 treatment is of concern. We identified a number of barriers to information needs being met, including the
17 perceived knowledge and attitudes of health professionals, the context in which information is given and the
18 nature of resources supporting information exchange. Finally, we have shown that unmet information needs can
19 have far reaching consequences in terms of adherence to treatment, relationships with health professionals and
20 augmenting the physical and psychosocial morbidity associated with the condition.

21

22 Wluka et al. have previously conducted an extensive review of health information needs across a range of
23 musculoskeletal conditions (29)]. This review reported that patients with rheumatoid arthritis (RA) and
24 osteoarthritis (OA) also want to know more about the nature of the condition, as we have found. Osteoarthritis
25 and osteoporosis are often confused (29)] and both are strongly associated with ageing; however, the findings in
26 this review and work in OA illustrate the negative impact on engagement with treatment if patients (and/or their
27 clinicians) attribute their condition solely to ageing (29, 30)]. The finding that fracture risk assessments were
28 questioned aligns with large multicentre epidemiological study that demonstrates that postmenopausal women
29 most at risk underestimate their own fracture risk (31)]. How best to communicate fracture risk is not well
30 established; although treatment decision aids which communicate fracture risk have been shown to improve

1 rates of treatment adherence in small studies they have not been qualitatively evaluated (32-34)]. The review by
2 Wluka et al. also reported that more information on self-management was wanted across all musculoskeletal
3 conditions, with patients with OA also wanting more information on prognosis, and those with RA also needing
4 more explanation about the purpose of medication (29)]. Unique to osteoporosis it would seem, is the need for
5 more education and support around long term treatment, to improve communication around the monitoring of
6 the so-called 'silent disease' and the effects of treatment. This may not be solely an issue around information as
7 it is likely to be influenced by models of care for patients with osteoporosis, and the lack of formal procedures
8 for monitoring the condition.

9
10 The factors we identified influencing whether information needs are met, include the observation that some
11 reported health information was too complex for some to understand, indicating low health literacy, which is
12 likely to be a major contributor to unmet need. Health literacy is defined as the personal characteristics and
13 social resources needed for individuals and communities to access, understand, appraise and use information
14 and services to make decisions about health; in the UK, the majority of patient health information is too
15 complex for 43% of the population who have limited health literacy (35, 36)].

16
17 We also identified perceptions that osteoporosis was not of interest to clinicians; there is little qualitative
18 research exploring the perceptions of primary care providers regarding osteoporosis but the limited evidence
19 available does suggest the condition may carry a low priority when compared to other long-term conditions such
20 as cardiovascular disease (37)], and that these clinicians may have their own educational needs regarding
21 osteoporosis (37, 38)]. Furthermore, research with primary and secondary care clinicians suggest they
22 underestimate the impact of the condition on their patients (39)]. Not all information needs of patients need to be
23 met by clinicians or specifically doctors, and many of the studies in this review describe how people use allied
24 health professionals e.g. pharmacists and dieticians, their social networks and other organisations to gain
25 information. Participants expressed great satisfaction with information resources available from third sector
26 organisations such as the NOS in previous focus groups conducted by our group (7)]. However, the information
27 giving in healthcare settings may need to be given a greater priority and be consistent with that given in other
28 contexts.

29

1 We have described the impact of unmet information needs. We have inferred that psychosocial morbidity has
2 occurred as a result of information needs being unmet, although in practice it is impossible to completely
3 disentangle the impact of unmet information needs from the physical effects of the condition e.g. vertebral
4 fractures. However, unmet informational needs are very likely to be a determinant of health, evidenced by the
5 association with health literacy and poor health outcomes which is well documented (40, 41)]. Furthermore, and
6 of relevance to osteoporosis, those with limited health literacy skills receive an inefficient mix of health care
7 services, with care biased towards acute and emergency care rather than planned and preventative care (42, 43)].
8 Adherence and persistence with bisphosphonates is known to be suboptimal and presents a major barrier to
9 treating osteoporosis in a clinically and cost-effective manner. The findings of this synthesis reinforce the notion
10 that addressing the beliefs and motivations of patients is of central importance in improving adherence (20)]. In
11 a systematic review of interventions designed to promote adherence, educational interventions targeted at
12 patients had mixed results (44)]. However, the content of these interventions and the theoretical basis on which
13 they were framed is not well described, with only one study reporting attempts to elicit beliefs which may
14 represent barriers to treatment (45)].

15

16 *Strengths and limitations:*

17 Augmented by the help of an information specialist, this review involved a comprehensive search of available
18 literature on expressed information needs of patients with osteoporosis/fragility fractures. The use of multiple
19 researchers to identify relevant literature, undertake quality assessments and code data also strengthened the
20 review. The use of very broad search terms resulted in a large number of studies to review but also meant that
21 relevant studies were not missed. The included studies cover a wide range of different experiences, including a
22 range of gender, age, ethnicity and nationality, thus giving a full overview of currently available evidence on
23 information needs among patients with osteoporosis. A further strength of this review is the exclusion of studies
24 that tested knowledge to ensure that the findings relate to patient expressed needs, unlike previous reviews in
25 this area (29)]. We used quality assessment to both inform results and underpin conclusions. However, no study
26 was excluded based on methodological quality and the heterogeneity of studies may limit the robustness of the
27 synthesis.

28 A number of other limitations are worthy of mention. First, the population of the included studies was relatively
29 diverse including patients with or without fracture, and either with osteoporosis or deemed at high fracture risk,
30 reflecting the change in clinical practice over the last decade to recommend fracture prevention treatments based

1 on fracture risk rather than the presence or absence of osteoporosis. It is possible that these clinical
2 characteristics may influence information needs. In particular, how patients make sense of being given treatment
3 for a condition they may not have, needs to be determined. One factor which limited interpretation of the
4 findings was that it was not always clear whether authors and/or participants were referring to primary or
5 secondary care healthcare professionals in their descriptions (23)]. Issues relating to information needs may vary
6 considerably across countries and different healthcare contexts which may limit the generalisability of our
7 findings. ~~Furthermore While we noted that all included , although the~~ studies were ~~all~~ published within the last
8 10 years, changes in clinical practice may make some issues more or less relevant to contemporary healthcare
9 settings. ~~In particular, o~~Our findings do not cover the use of the internet or the influence of the many and
10 multiple media reports regarding osteoporosis and the safety of osteoporosis treatments that have emerged over
11 recent years. This is of particular importance because fear of side effects is an important deterrent to patients
12 initiating treatment , and there is some evidence to suggest that these media stories are influencing clinicians as
13 well as patients. Finally, as only three included studies were focused on information giving and needs, and in
14 some studies, little data was relevant for extraction, it is possible that there remain issues not covered by this
15 review.

Comment [p5]: <https://www.ncbi.nlm.nih.gov/pubmed/26018247>

Comment [p6]: [http://www.japha.org/article/S1544-3191\(17\)30682-9/abstract](http://www.japha.org/article/S1544-3191(17)30682-9/abstract)

Comment [p7]: <https://www.ncbi.nlm.nih.gov/pubmed/25792490>

17 *Implications for practice and research:*

18 These findings raise important implications for clinical practice at the level of individual clinicians, services and
19 wider organisations. First, health professionals (including doctors, pharmacists and nurses) involved in the care
20 of patients with osteoporosis should reflect on to what extent they elicit or facilitate the expression of
21 information needs and to what extent their core explanations relating to osteoporosis address issues about the
22 nature of the condition, the purpose of medication and holistic approach to management. Second, at a service
23 level, primary and secondary care services might consider the follow up pathways for these patients and how
24 these pathways are communicated to patients. Third, we suggest there is an urgent need for organisations and
25 other providers of written information relating to osteoporosis and osteoporosis medication to ensure that
26 material is easily understandable to those with limited health literacy. There are a number of freely available
27 online tools that can evaluate ease of readability.

29 In terms of implications for research, our review has not addressed the way osteoporosis and its treatment is
30 conceptualised in the media, and the implications of this for patient care and this remains an area where further

1 | study is needed. Understanding this societal context is critical to inform the design of public health messages. In
2 | terms of the clinician-patient encounter, the findings highlight the need to understand further healthcare
3 | professionals' attitudes to osteoporosis, particularly that of GPs and primary care providers, and to understand
4 | the barriers to the provision of information in healthcare settings. The findings support the hypothesis that
5 | educational interventions may promote treatment adherence, but any further research in this area needs to ensure
6 | interventions are co-designed with patients, to ensure they are relevant to their needs, are applicable to a range
7 | of health literacy abilities and that the content of the interventions is explicitly mapped to the important health
8 | beliefs associated with non-adherence. Furthermore, evaluation of educational interventions should include
9 | outcomes that are patient-centred including satisfaction, self-efficacy and psychological measures. Finally, we
10 | suggest that further research is needed into the optimum ways of explaining osteoporosis and fracture risk to
11 | promote clear messages, avoid ambiguity and promote treatment persistence.

12

1 **Figures and Tables:**

2 **Fig. 1** Identification and selection of studies

3 **Fig. 2** Nature and consequences of unmet educational needs and factors promoting and impeding information
4 being given and received

5 **Table 1** Inclusion and exclusion criteria

6 **Table 2** Characteristics of included studies

7 **Table 3** Quality appraisal of included studies

8 **Table 14** Authors reported main findings and extracted information needs

9

10 **Supplementary material:**

11 Search Strategy

12 **Table 5** Search terms

13 **Table 6** Hawker et al. quality appraisal framework¹ (11)]

14

¹ Each item was given a score of either good (4 points), fair (3 points), poor (2 points) or very poor (1 point), giving a total score out of 36.

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