

# How do osteoporosis patients perceive their illness and treatment? Implications for clinical practice

Sarah Jane Besser · Janet E. Anderson · John Weinman

Received: 12 April 2012 / Accepted: 18 June 2012

© International Osteoporosis Foundation and National Osteoporosis Foundation 2012

## Abstract

**Summary** Non-adherence inhibits successful treatment of osteoporosis. This study used a theoretical framework to explore osteoporosis patients' cognitive and emotional representations of their illness and medication, using both interviews and drawing. We recorded some misconceptions patients have about their condition and medication which could act as barriers to treatment adherence.

**Purpose** Despite the high efficacy of current treatments in reducing fracture risk, poor adherence is still a problem in osteoporosis. This qualitative study aims to inform the development of a psychological intervention to increase adherence through the investigation of osteoporosis patients' perceptions of their illness and medication. The self-regulation model (Leventhal) provided the framework for the study.

**Method** Participants were 14 female outpatients from a London teaching hospital who suffer with osteoporosis or osteopenia. Data were collected using both semi-structured interviews and drawings. Drawings were used to elicit

participants' visual representations (imagery) of their condition.

**Results** We found that patients held illness and medication beliefs that were not in accord with current scientific evidence. Interviews revealed that participants had good knowledge of what osteoporosis is, but they had low understanding of the role of medication in reducing fracture risk, various concerns about the side effects of medication, poor understanding of the causes of osteoporosis and uncertainty about how it can be controlled. Additionally, drawings elicited more information about the perceived effects of osteoporosis and emotional reactions to the condition.

**Conclusions** Osteoporosis sufferers need a better understanding of their fracture risk and what they can do to control their condition. Concerns about medication need to be addressed in order to improve adherence, particularly in relation to the management of side effects. Since drawings of osteoporosis were found to arouse emotions, it is concluded that risk communication in osteoporosis could benefit from using visual images.

**Keywords** Adherence · Emotions · Illness perceptions · Medication beliefs · Visual representations

S. J. Besser (✉)

NIHR King's Patient Safety and Service Quality Research Centre,  
King's College London,  
2 Basement, 138-142 Strand Bridge House, Strand,  
London WC2R 1HH, UK  
e-mail: sarah.besser@kcl.ac.uk

J. E. Anderson

NIHR King's Patient Safety and Service Quality Research Centre,  
King's College London,  
Franklin Wilkins Building, 150 Stamford Street,  
London SE1 9NH, UK

J. Weinman

Institute of Psychiatry, Health Psychology Section,  
King's College London,  
Great Maze Pond,  
London SE1 9RT, UK

## Introduction

Osteoporosis is a common disease of the skeletal system in which bone mineral density (BMD) becomes reduced—resulting in brittle bones which break easily. In the UK it is estimated that one in two women and one in five men over the age of 50 will fracture a bone due to osteoporosis [1]. Osteopenia is a similar condition of lowered BMD which indicates bone deterioration and a high risk of developing osteoporosis [2]. The prevalence of osteoporosis in the UK is predicted to rise by a fifth over the next decade [3].

Osteoporotic fractures can result in pain, disability, loss of independence and poor quality of life for their sufferers. Research about patients' perceptions of osteoporosis and its treatment has predominantly taken place in the USA and Canada. In this study we investigated patients' perceptions of their illness, medication and the risk of fractures with female outpatients from a London (UK) teaching hospital. The study is part of a larger project with the aim of designing an intervention to improve adherence, using the Medical Research Council's framework for the design and evaluation of complex interventions [4]. The aim of the present study was to explore patients' perceptions of their illness and identify potential areas for intervention to improve treatment adherence.

Non-adherence is a major barrier to effective healthcare. Adherence is defined as the extent to which patients follow their treatment recommendations [5], including medication taking and attending clinic appointments [6]. Various medications have been developed which can significantly reduce the risk of osteoporotic fractures [7], but treatment efficacy is compromised by poor adherence. Researchers estimate that 50 % of patients do not take their osteoporosis medication as prescribed [8], but adherence is difficult to measure and osteoporosis clinicians suggest it is likely to be even lower than that detected by researchers.

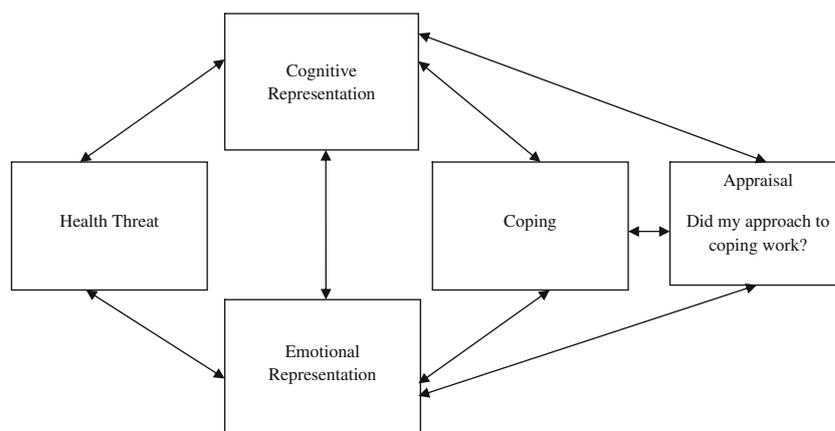
There is a pressing need for health behaviour change interventions to improve treatment adherence, to reduce the risk of fracture and the healthcare costs involved, particularly for medical conditions which have effective medications to treat them [9]. It has been noted that 'increasing the effectiveness of adherence interventions may have a far greater impact on the health of the population than any improvement in specific medical treatments' [9]. Interventions should be based on evidence about the psychological factors that underpin non-adherence and how they can be modified. For example, erroneous beliefs about the effects of medication could be modified with a psycho-educational intervention, and emotional responses such as depression

could be altered by the provision of support, medication or psychotherapeutic counselling.

Psychological factors have been found to predict adherence to medication in a variety of chronic conditions [10], and there is some evidence that this is the case with osteoporosis. For example, researchers have found that patients' beliefs about their perceived need for medication, concerns about medication, experience of side effects and the inconvenience of dosing regimens are all associated with non-adherence [11, 12]. Lowered perceptions of the risks of osteoporosis could also contribute to medication non-adherence. Studies have found that even patients who had previously sustained a fragility fracture thought that their risk of a future fracture was not high [13, 14], suggesting that they might not perceive the need for osteoporosis medication. Moreover, these studies found that fracture patients attributed the cause of their fractures to falls rather than to osteoporosis.

Previous studies of adherence in osteoporosis patients have examined only some of the relevant psychological factors, such as the perceived need for medication and concerns about taking it. [12]. In this study we used Leventhal's self-regulation model (SRM) (see Fig. 1) to investigate perceived health threat, cognitive representations, medication beliefs and emotional responses to osteoporosis [15]. The SRM posits that adherence is influenced by cognitions (or beliefs) and emotional responses to the illness. According to the model, adherence is viewed as a positive coping strategy that is influenced by both cognitive and emotional representations of the illness. Cognitive representations include beliefs about the identity, cause, timeline, controllability/cure and consequence of the illness. This is a dynamic model, meaning that as beliefs change, coping mechanisms also change. The model's author suggests that patients' personal understanding of their illness needs to be coherent in order for them to cope effectively. Since its development, the SRM has been extended to include medication beliefs (perceived need and concerns) [16]. Medication beliefs have

**Fig. 1** The self-regulation model (adapted from Leventhal et al. [15])



been found to predict adherence in a variety of conditions [17] including osteoporosis [12]. The addition of medication beliefs to the self-regulation model makes it useful for exploring adherence to medication.

The SRM has been applied in many studies of adherence for other medical conditions, such as diabetes [18] and coronary heart disease [19]. Using the framework of the SRM allows us to systematically examine a range of cognitive and emotional responses to osteoporosis and its treatment.

The aim of the present study was to explore how osteoporosis patients perceive their illness and treatment, to provide an evidence base for investigating adherence and how to improve it. The objectives were to explore how osteoporosis patients view their illness, to identify what beliefs they hold about their illness and medication and to identify how they view their fracture risk. We used two approaches to explore how patients perceive their illness and treatment; these were semi-structured interviews and patients' drawings of their condition. Drawing has been used in previous studies of heart disease [20] and cancer [21] to explore patients' understanding of and adaptation to their illness. Further, drawing is a powerful method of eliciting responses that would be difficult for patients to articulate because of their emotional salience [22]. We anticipated that the asymptomatic nature of osteoporosis might make it difficult for patients to describe how they perceived the condition and its impact, and that drawing would provide greater insight into these issues than interviews alone.

## Method

### Study design

Semi-structured interviews were used to collect information. The design of the interview schedule was based upon the dimensions of the SRM [15] and informed by feedback from expert patients and service users. Questions covered the following topics: identity (or illness label), causes of osteoporosis, consequences, timeline, controllability of the disease, emotions experienced, treatment(s) prescribed, treatment concerns, confidence in adhering to treatment and motivation to manage the condition. Patient drawings were made during the interviews. The study was carried out in a London teaching hospital.

### Participants

Fourteen women (outpatients) with osteoporosis ( $n=10$ ) or osteopenia ( $n=4$ ) were interviewed. Men were excluded from this study because osteoporosis is more common in women and it is likely that there are different explanatory factors for non-adherence in men. Their mean age was 69

(SD=10.1), and the mean time since diagnosis was 7.9 years (three participants could not remember when they were diagnosed). They had experienced on average 2.8 fractures (range, 0–8). Nine of the women attended their last clinic appointment and five did not. We included non-attending patients because they are potentially non-adherent to medication and thus could provide insights into factors related to non-adherence. Participants were included if they had been diagnosed with osteoporosis/osteopenia for at least 6 months and were prescribed osteoporosis medication. The sample was recruited from both the osteoporosis screening unit and the rheumatology clinic. Participants were excluded if they were male, not prescribed osteoporosis medication or did not speak English.

### Recruitment

Patients meeting the inclusion criteria were identified by the clinic doctor and sent postal invitations with the participant information sheet. Those who agreed to be interviewed for the study were asked to sign and return the consent form. Participants were then contacted by a researcher to arrange an interview time. A small sum (£5 GBP) was offered to participants to cover the cost of expenses. The sample of attending patients was women who had recently taken part in a different research project at the clinic and who met the inclusion criteria. The sample of non-attending patients was identified by the medical secretary who provided a list of patients who had not attended their rheumatology clinic appointment for the last 3 months. For the attending group 9 of 15 (60 %) responded and agreed to take part. The response rate was lower for the non-attendant group, 5 of 29 (17 %).

### Procedure

Ethical approval was obtained from the South West London Research Ethics Committee. All participants gave informed consent to take part in the study. Interviews were conducted in a private room and took between 30 and 75 min. They were audio recorded for later analysis. At the end of the interview, all participants were asked to draw a bone with and without osteoporosis. In addition, seven participants were asked to draw a person with and without osteoporosis. Participants were instructed to draw stick figures to make the task easier. The interviewer then asked them to verbally describe their drawings and their feelings about the drawings.

### Data analysis

Interviews were transcribed verbatim and analysed using a coding framework derived from the interview questions

[23]. Data were managed using Nvivo, version 9. Two independent researchers coded two transcripts each to ensure reliability of the coding framework. Discrepancies between the researchers' interpretations were discussed and resolved. There were 14 drawings of bones and 7 drawings of people with osteoporosis. Participants' drawings of bones and people were analysed by identifying the themes represented, analysing the size and shape of the bone drawings and identifying the deformities depicted. To validate the findings three independent researchers coded the participants' drawings.

## Results

Thirteen global themes were initially generated with 59 themes and 129 sub-themes. These were aggregated by grouping together the global themes where it was appropriate to do so and through discussion with other coders. This process produced 10 global themes, 31 themes and 25 sub-themes. An overview of the themes with representative quotes for each is shown in Table 1.

In the following sections we present data from each of the ten global themes. Due to the large amount of data generated by this study, only themes which were discussed by two or more people are presented (unless stated). Drawings of bones and people with and without osteoporosis are also presented.

### Identity (illness label)

This theme describes what people understand about osteoporosis. Participants showed good knowledge of osteoporotic bones having reduced bone mineral density and being brittle and easy to break. However, some participants doubted whether osteoporosis is asymptomatic and described a range of symptoms that they attributed to osteoporosis (e.g. pain, flaky nails, rotting teeth). The drawings of bones provided further insight into how patients view their condition (see Fig. 2 below). They generally indicated a good understanding of the effect of osteoporosis on bone structure. Drawings of osteoporotic bones depicted damage to the internal structure of the bone (drawn by ten participants) or to the outer edge of the bone (three participants). Two participants correctly identified damage to both the internal and external bone structure. Drawings of bones with and without osteoporosis did not differ significantly in length or width.

### Causes

Participants were asked about the causes of osteoporosis in general as well as the cause of their own osteoporosis. They

were able to list potential causes of osteoporosis in general, but found it difficult to give a reason for their own osteoporosis. When discussing the cause of their own fractures, many participants reported that their fractures were a result of factors other than osteoporosis; they attributed their fractures to falls or other medical conditions such as glaucoma, which resulted in low visual acuity. Some also commented that not only people with osteoporosis suffer from fractures and conversely that not all fractures are a result of osteoporosis.

### Timeline

Participants demonstrated good understanding that osteoporosis is a chronic condition. However, some participants were confused that while the condition is chronic and incurable, they are only required to take their treatment (bisphosphonates) for 5 years.

### Controllability/cure

All participants understood there is no cure for osteoporosis, though some said that they hoped for a cure in the future. Most participants clearly stated that they could control osteoporosis by preventing themselves from falling over. Apart from falls prevention they were unclear about how to control the condition. One participant reported that she had never been given any dietary information in relation to the condition and therefore believed that there was no link between osteoporosis and diet (see Table 1). Lack of understanding regarding the controllability of osteoporosis was revealed by many participants who questioned the interviewer about how to control it. Participants were asked about whether they thought medication could prevent fractures; 50 % of participants reported that they had not thought about the role of medication in reducing their risk and preventing fractures.

### Consequences

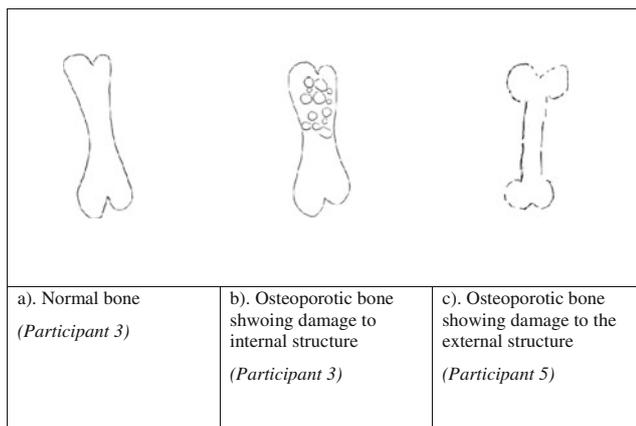
During the interview, participants commonly reported that having osteoporosis did not have much impact on them and they did not think about it daily. The physical consequences discussed by participants were: spine curvature, loss of height, hospitalization, brittle bones, disability and chronic pain from fractures. The majority of people discussed spine curvature, especially when asked what osteoporosis is. Very few participants noted mortality to be a consequence of osteoporosis.

Some participants responded that osteoporosis limited their activity. As well as mentioning that being more careful is a method of controlling osteoporosis, participants noted that it limited their activity by causing them to be careful.

**Table 1** Overview of themes

Theme <sup>a</sup>	Quote
<b>Identity</b>	“I know they say osteoporosis is painless, I can’t really believe that.” (participant 14)
<b>Cause</b>	“I think anyone who would have fallen like that would have fractured. It was a hard fall. I am not able to see all that well so I think this is why I fell over.” (participant 2)
<b>Timeline</b>	“You don’t get rid of it, do you?” (participant 12)
<b>Controllability</b>	“Nobody’s ever said to me, if you did this or did that, or ate this or ate that, nobody’s ever given me a diet sheet connected with it, so presumably the powers that be don’t believe diet has anything to do with it because nobody’s ever given me anything to say do this.” (participant 8)
<b>Cure</b>	“I don’t know, is weight a burden on the bones, or do they need a bit of weight to be good bones? I’m too ignorant about it.” (participant 8)
<b>Consequences</b>	“Oh sorry, well I think once you’ve got it, it’s there, isn’t it, forever.” (participant 11)
<b>Emotions</b>	“It doesn’t affect me at all, I have no symptoms. The only way it affects me is that I have to take medication.” (participant 1)
<b>Risk perceptions</b>	“No, I’ve been lucky. Touch wood... I’m scared of falling over or... that is a fear.” (participant 11)
Severity	“Well yes, it is a serious condition I think, mainly because of fractures and the disability it causes.” (participant 1)
Susceptibility	“It’s the same, well I mean you never know who is going to be hit by a bus, this would cause anyone to fracture, so I’m not at more risk.” (participant 1)
<b>Medication beliefs</b>	
General	“Doctors are enthusiastic to give medicines because that’s what they do. I am keen to kind of make sure that it’s what I really need.” (participant 13)
	“Because it must harm the insides somehow to keep taking pills. And if you’ve got a few things wrong with you and if you’ve got all these things mixed up inside, all these different problems, surely in the long run it don’t help.” (participant 11)
Osteoporosis medicine	“The components of bisphosphonates are not a lot different to, em, the chemicals they use to clean machine parts.” (participant 7)
	“I’d read the leaflet about the oesophagus, and a friend... had just died with having cancer of the oesophagus. And it was pretty awful evidently, so I thought, I don’t fancy that...It probably doesn’t happen to many people, but once you start getting any sort of side effects, you think, oh maybe it’s doing it to me.” (participant 5)
<b>Adherence</b>	“Sometimes on a Sunday I forgot, but you can take that the next day, so you just take it on the Monday, I’ve done that a few times.” (participant 4)
Feedback as a facilitator of adherence	“So they actually feedback to you, and that made you realise it was good to take it.” (participant 14)
<b>Recommendations for adherence</b>	
Using pictures	“I also think that showing patients pictures of bones could be useful in helping them to understand what is going on.” (participant 1)
Medication instructions	“To understand those you need a doctorate, or a good degree...and a degree in kind of medical terms.” (participant 8)
<b>Relationships</b>	
Doctor–patient relationships	“I think you’re treated in quite a child-like way, you’ve got to stand up for an hour. Okay, I can do that, why?”(participant 7)
	“I’ve got a very sympathetic doctor, he’ll talk to me and listen to me, and if he says do something, I’ll do it you know.” (participant 9)
Social support	“I just remember on a Sunday morning I have to have it, and my husband now he’s got into the habit—have you had your medicine? And then sometimes I say oh no!” (participant 4)

<sup>a</sup>Bold text indicates a high-level theme; normal text indicates a sub-theme



**Fig. 2** Examples of participants' drawings of bones with and without osteoporosis

Participants' drawings of the consequences of osteoporosis elicited more discussion about its personal impact than the semi-structured interview questions about consequences. The drawings commonly emphasised spine curvature and loss of height as major consequences of osteoporosis (shown in Fig. 3 below).

#### Emotions

When asked directly, many participants reported that having osteoporosis did not affect them emotionally and reported

feeling lucky that they had caught their osteoporosis early. Over half of the participants reported that they felt no emotion in relation to the condition when asked directly, because it had little impact on their daily lives. However, when asked to describe how they felt about their drawings of osteoporosis, many participants described strong emotional responses to the illness. For example, during the interview questions, one participant said she did not really think about osteoporosis, but then, when looking at her drawing, she reported feeling angry that her back had become curved. Concerns discussed by the participants included: fear of being wheelchair bound, fear of fractures, fear of falling and, most commonly, fear of having a curved upper spine. Other emotions discussed were shock, worry and anger.

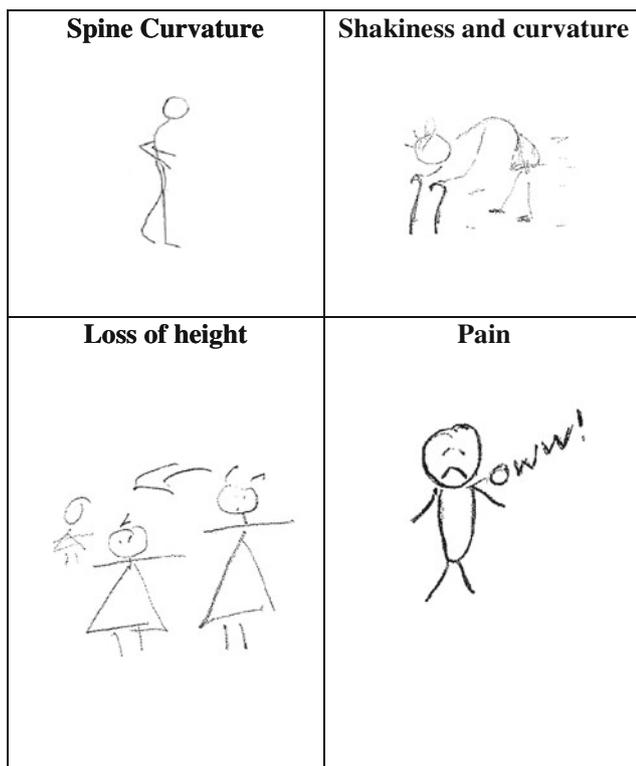
#### Risk perceptions

When asked about the seriousness of osteoporosis in general, all participants reported that it was serious. However, many also reported that their own personal osteoporosis was not severe. Some patients were unsure about how serious it was for them personally. There was a range of responses regarding susceptibility to fracture. It was most common for participants to report that their fracture risk in the next year was the same or lower than that of others of their age. Some believed that their fracture risk was low because they were able to change their behaviour to reduce the risk of falls.

#### Medication beliefs

Half of the sample said medication in general was positive. Half of the participants listed various concerns about medication in general including: side effects, harmfulness, over prescribing, addiction, suspicion of pharmaceutical companies, dislike of chemicals, drug interactions and overdosing. Participants in the 'did not attend' group had more concerns about medication in general and about osteoporosis medication specifically than attendees. Many participants expressed concerns about media reports of the link between bisphosphonates and oesophageal cancer.

There was a range of responses about the administration of osteoporosis medication. The majority said that it was easy to administer; however, some participants reported that it was frightening to take, because of its potential effects on the oesophagus. Two participants commented that while they found it easy to take their medication, older relatives with osteoporosis found it much more difficult. It was evident that there was a common misinterpretation of medication instructions. Some participants thought they had to remain still after administering the medication.



**Fig. 3** Participant drawings of the impact of osteoporosis

## Adherence

Participants discussed their adherence to the various treatments prescribed throughout the course of their condition. The majority of patients reported excellent adherence to their osteoporosis medication. However, one patient had decided not to take medication, one was deliberating whether to take it and some reported stopping and changing to a different osteoporosis medication due to experiencing side effects. Apart from side effects, the most common reasons given for missing a dose were unintentional, including: forgetting, altering the time of taking the dose and change of routine. Conversely, it was commonly reported that receiving feedback such as the results of a bone scan helped people to realise that medication was beneficial. Consequently, feedback was reported as increasing motivation for adherence.

## Relationships

The doctor–patient relationship was reported by all of the participants to be an important factor which affected adherence. Some participants reported that a good relationship with their doctor facilitated adherence. On the other hand some reported negative relationships with their doctor, aspects of which included: lack of time during consultation, poor communication, lack of continuity of care and one participant reported concern for the apparent lack of knowledge in relation to osteoporosis shown by their doctor.

It was evident from the results of this study that social support was interpreted as either helpful or unhelpful; some patients were reminded to take their medication by their families and were prompted to go for osteoporosis screening. Medication advice was also given by relatives, including advice to stop the medication when side effects were experienced. It was not clear whether such information giving from the relative was accurate.

## Recommendations for helping future patients to take their medication

Participants were asked what could be done to improve medication adherence. Recommendations were categorised into four sub-themes: communication and education, monitoring, planning and patient-centred care. Recommendations for ‘communication and education’ included: using pictures to communicate the risks involved in having osteoporosis as a condition, providing more information about the illness and its treatment including the reasons for treatment directions, altering the medication instructions to make them more understandable and providing information on the long-term effects of medicines. Recommendations for ‘monitoring’ included regular DEXA scan feedback and

introducing medication reviews. ‘Planning’ recommendations included: using a tablet organiser and emphasising the importance of routine. Lastly, some participants recommended that patients need to be involved to a greater extent in decisions related to treatment.

## Discussion

This study used the extended self-regulation framework and a novel drawing method to explore psychological factors in osteoporosis. The results have implications for interventions to improve adherence to osteoporosis medication. Many osteoporosis patients in this study revealed misconceptions about the illness and management of the condition including misunderstanding and concerns about osteoporosis medication. The results confirm those of other studies showing that osteoporosis patients have inaccurate perceptions of their own fracture risk [13], attribute fractures to their own behaviour rather than osteoporosis [14] and have concerns about the safety and side effects of osteoporosis medication [11, 12]. Most importantly, this study confirmed previous findings that the link between osteoporosis and fracture risk and the role of medication was difficult for participants to comprehend [13, 14]. Using the SRM theory to systematically examine the relevant psychological constructs generated new insights into specific knowledge deficits.

Participants demonstrated a lack of understanding of many specific aspects of osteoporosis and its treatment. There was confusion about symptoms, personal causes of osteoporosis and fractures, methods of control and the medication timeline (for bisphosphonates). Further, patients did not know or understand that medication could reduce the risk of fractures. Unrealistically low-risk perceptions are commonly found across medical conditions and may indicate optimistic bias [24], which might reflect an avoidant coping mechanism. The majority of patients knew they would have this condition for the rest of their lives. However, some were puzzled that they were nevertheless not required to take medication for the duration of their condition, indicating a possible mismatch between their perceptions of the timelines of their condition and of their treatment. Drawings indicated that some patients did not understand that normal bones are porous and that bone damage in osteoporosis is both internal and external. The absence of a size difference in patients' drawings of bones with and without osteoporosis also indicates lack of insight into the fact that osteoporotic bones would be expected to be thinner than normal bones. Some patients reported symptoms in the early stages of osteoporosis indicating that they may perceive symptoms as a response to their diagnosis. A similar phenomenon has been demonstrated in hypertension [25].

In line with previous research findings [13, 14], some participants attributed the causes of their fractures to falls or sight problems rather than osteoporosis. It appears that patients view the proximal cause of a fracture (e.g. falling) to be more important than the distal cause—bone fragility. Previous studies have demonstrated that myocardial infarction patients perceive a network of both proximal and distal causes of their heart attack [26], and we found a similar pattern in osteoporosis. The fact that some patients attributed fractures to falling rather than bone fragility is problematic, because it may influence how they choose to manage the condition, e.g. they may choose falls prevention over medication as a management strategy whereas both strategies are important.

Clinical practice could benefit from introducing psycho-educational interventions to assist patients to develop a more accurate understanding of the disease whereby fractures are understood to be caused by a combination of poor bone health and a precipitating event, such as a fall. The study identified many specific misunderstandings that could be addressed by education, but patients differed in their information needs and there was a range of knowledge. This suggests the need for patient-centred tailored information that addresses their particular needs and enables them to develop a coherent mental representation of their illness and its management [9].

Previous research has found that medication beliefs predict adherence in osteoporosis [12]. Negative beliefs about medication in general and about osteoporosis medication were identified in this study, and these were more frequent in non-attending patients, suggesting that this group may be at high risk of non-adherence and should be engaged by healthcare professionals. Potential interventions could involve the provision of psycho-educational material about osteoporosis and following up to ascertain reasons for non-attendance. The most commonly discussed concern about osteoporosis medication was side effects, particularly oesophageal damage. Recent media reports about a link between oesophageal cancer and osteoporosis medication were a concern for patients. Patients' concerns about side effects and fears of potential side effects need to be addressed—particularly the extent to which they should tolerate minor side effects. Additionally, medication instructions should be adjusted so that patients understand that they can move after taking their bisphosphonates, as long as they do not lie down. Potential interventions to address negative medication beliefs include the provision of information and motivational interviewing to help patients to tolerate side effects and generate self-motivating statements about the benefits of medication.

The contrast between participants' responses to questions about the causes of osteoporosis in general and their own osteoporosis is interesting. When asked about personal beliefs for the cause of their condition,

participants most commonly reported hereditary reasons rather than environmental or behavioural causes. The fact that participants could talk more freely about the causes of osteoporosis in general rather than the cause of their own condition could suggest lack of knowledge or acceptance that lifestyle plays a role in the development of osteoporosis. Participants may find it psychologically protective to attribute osteoporosis to an uncontrollable cause such as genetic predisposition rather than to their own behaviour. This clearly has implications for adherence to treatment; viewing osteoporosis as uncontrollable may be related to non-adherence. Psycho-education interventions should highlight the various methods of controlling osteoporosis.

Other findings with implications for interventions include social support and feedback. Social support can have a positive or negative impact on adherence. The doctor–patient relationship featured as very important in patients' decisions about following treatment advice—as shown in previous studies [27, 28]. Patients commented that when they had a good relationship with their doctor, they wanted to follow their instructions. Improved doctor–patient communication can be incorporated into future interventions, including education for healthcare professionals and students about the impact of their relationship with patients on adherence. Relationships should also be supportive and address the fears and concerns that patients have about osteoporosis, but may have difficulty expressing. Feedback from BMD scans was a crucial motivator of adherence for this group. Scans provide concrete information about disease progression, which is fundamentally important in a condition which is asymptomatic and often invisible to the patient.

The process of drawing elicited powerful emotions from patients. During the interviews, many patients reported no emotional response to osteoporosis, possibly because, for many, it was asymptomatic. However, drawing visual representations of the disease and discussing them elicited strong emotional reactions. Visual representations of osteoporosis may therefore have utility in future interventions to inform patients of the effects of the condition and to motivate adherence. However, the use of emotionally salient images needs to be carefully considered; negative emotions can motivate behaviour changes, but can also lead to avoidant responses if patients feel helpless [29].

Future interventions in clinical practice to facilitate adherence to osteoporosis medication could build on findings from this study. To address patients' misconceptions about their condition, interventions could focus on psycho-education for patients as well as education for doctors about the importance of emphasising adherence to treatment. Patients suggested that visual images

of osteoporosis would be beneficial in helping them to have a clearer understanding of their condition. This study suggests that education for patients should focus on the causes of osteoporosis and methods of managing fracture risk.

### Limitations

The study was designed to investigate psychological factors in osteoporosis in order to inform potential interventions to improve adherence. A major challenge in investigating adherence is that patients who agree to take part in research studies are likely to be those who are adherent to their doctor's treatment recommendations. We included patients who had not attended their last clinic appointment in order to mitigate this factor. Nevertheless, most participants in the study reported good adherence, and we did not measure adherence. Although this does not invalidate the findings, it means we should exercise caution in drawing conclusions about those patients who may not be adherent. A further limitation of this study is the exclusion of men. It is possible that different psychological factors are related to treatment adherence in men, which need to be explored by further research.

### Conclusions

Osteoporosis patients are required to self-manage their fracture risk, often while managing multiple co-morbidities. The SRM framework was useful in exploring the cognitive and emotional responses to osteoporosis and its treatment. Findings from this study are directly relevant to the design of interventions to improve adherence. These are: (1) some patients are unaware that osteoporosis medication can reduce the risk of fracture; (2) drawings/images of osteoporosis may arouse emotions in patients and could be used to help them to understand the seriousness of the condition; (3) some patients have limited knowledge/ideas about the causes of their condition; (4) there is confusion and uncertainty about how/whether the condition can be controlled and (5) patients who do not attend clinic appointments may be at particular risk of medication non-adherence.

In this study we found that non-attending patients expressed more concerns about medication than attending patients. This implies that including non-attending patients in future adherence intervention studies is essential because medication concerns have been previously found to predict treatment adherence. This study suggests that non-attenders are a group who may have more problems in relation to following treatment recommendations. It would be beneficial for future researchers to investigate the extent of non-adherence in patients who do not attend their clinic appointments.

**Acknowledgments** This article presents independent research commissioned by the National Institute for Health Research. The views expressed in this publication are those of the authors and not necessarily those of the NHS, NIHR or the Department of Health. We would like to thank Dr. Amelia Moore, the expert patients who assisted the study design, Dr. Alastair Ross, Dr. Nao Kadote, Dr. Kellie Thompson and Dr. Angus Ramsay for validation of data coding.

**Conflicts of interest** None.

### References

1. Van Staa TP et al (2001) Epidemiology of fractures in England and Wales. *Bone* 29(6):517–522
2. Kanis JA et al (1994) The diagnosis of osteoporosis. *J Bone Miner Res* 9(8):1137–1141
3. Gauthier A et al (2011) Epidemiological burden of postmenopausal osteoporosis in the UK from 2010 to 2021: estimations from a disease model. *Arch Osteoporos* 6(1):179–188
4. Campbell M et al (2000) Framework for design and evaluation of complex interventions to improve health. *BMJ* 321:694–696
5. Haynes R et al (2002) Interventions for helping patients to follow prescriptions for medications. *Cochrane Database Syst Rev* (2): CD000011
6. O'Donohue WT, Levensky ER (2006) Promoting treatment adherence: a practical handbook for health care providers. Sage Publications Inc, Thousand Oaks, p 458
7. Siris ES et al (2006) Adherence to bisphosphonate therapy and fracture rates in osteoporotic women: relationship to vertebral and nonvertebral fractures from 2 US claims databases. *Mayo Clin Proc* 81(8):1013–1022
8. Gleeson T et al (2009) Interventions to improve adherence and persistence with osteoporosis medications: a systematic literature review. *Osteoporos Int* 20(12):2127–2134
9. Home R et al (2005) Concordance, adherence and compliance in medicine taking. Report for the National Co-ordinating Centre for the NHS service delivery and organisation R & D (NCCSDO), pp 1–372
10. Petrie K, Weinman J (eds) (1997) Perceptions of health and illness. Current research and applications. Harwood Academic Publishers, Singapore, pp 1–17, Introduction to the perceptions of health and illness
11. Carr A, Thompson P, Cooper C (2006) Factors associated with adherence and persistence to bisphosphonate therapy in osteoporosis: a cross-sectional survey. *Osteoporos Int* 17(11):1638–1644
12. McHorney CA et al (2007) The impact of osteoporosis medication beliefs and side-effect experiences on non-adherence to oral bisphosphonates. *Curr Med Res Opin* 23(12):3137–3152
13. Giangregorio L et al (2008) Do patients perceive a link between a fragility fracture and osteoporosis? *BMC Musculoskelet Disord* 9(1):38
14. Giangregorio L et al (2009) Osteoporosis risk perceptions among patients who have sustained a fragility fracture. *Patient Educ Couns* 74(2):213–220
15. Leventhal H et al (1997) Illness representations: theoretical foundations. In: Petrie KJ, Weinman JA (eds) Perceptions of health and illness. Current research and applications. Harwood Academic, London, pp 19–45
16. Home R, Weinman J (1999) Patients' beliefs about prescribed medicines and their role in adherence to treatment in chronic physical illness. *J Psychosom Res* 47(6):555–567

17. Horne R (2003) Treatment perceptions and self regulation. In: Routledge (ed) *The self regulation of health and illness behaviour*. Taylor and Francis Group, London, pp 138–155
18. Broadbent E, Donkin L, Stroh JC (2011) Illness and treatment perceptions are associated with adherence to medications, diet, and exercise in diabetic patients. *Diabetes Care* 34(2):338–340
19. French DP, Cooper A, Weinman J (2006) Illness perceptions predict attendance at cardiac rehabilitation following acute myocardial infarction: a systematic review with meta-analysis. *J Psychosom Res* 61(6):757–767
20. Broadbent E et al (2006) Changes in patient drawings of the heart identify slow recovery after myocardial infarction. *Psychosom Med* 68(6):910–913
21. Harrow A et al (2008) Seeing is believing, and believing is seeing: an exploration of the meaning and impact of women's mental images of their breast cancer and their potential origins. *Patient Educ Couns* 73(2):339–346
22. Guillemin M (2004) Understanding illness: using drawings as a research method. *Qual Health Res* 14(2):272–289
23. Ritchie J, Spencer L et al (2003) Carrying out qualitative analysis. *Carrying out qualitative analysis in qualitative research in practice*. Sage, London
24. Weinstein ND (1989) Optimistic biases about personal risks. *Science* 246(4935):1232–1233
25. Baumann LJ et al (1989) Illness representations and matching labels with symptoms. *Health Psychol* 8(4):449–469
26. French DP et al (2002) The structure of beliefs about the causes of heart attacks: a network analysis. *Br J Health Psychol* 7(Part 4):463–479
27. Lau E et al (2008) Patients' adherence to osteoporosis therapy: exploring the perceptions of postmenopausal women. *Can Fam Physician* 54(3):394–402
28. Zolnieriek KB, Dimatteo MR (2009) Physician communication and patient adherence to treatment: a meta-analysis. *Med Care* 47(8):826–834
29. Witte K (1992) Putting the fear back into fear appeals: the extended parallel process model. *Commun Monogr* 59(4):329–349