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## RESEARCH ARTICLE

# Screening for Underlying Osteoporosis in Fragility Fracture Patients: The Patients Perspective

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### Abstract:

#### Background:

Early detection and treatment of osteoporosis are essential in preventing fractures and fracture-related morbidity and mortality. Fractures beget fractures and it is relevant, well-documented and beneficial to target osteoporosis screening in patients already suffering from a fracture. The associated increased number of patients being confronted with a potential diagnosis of osteoporosis makes it worth considering how this affects patients.

#### Objective:

The aim of this study was to explore fracture patients' experiences when confronted with the option of being screened for osteoporosis as the underlying reason of their fracture.

#### Methods:

In a phenomenological hermeneutic framework, semi-structured interviews were performed in 15 fragility fracture patients being offered screening for osteoporosis. Analysis inspired by Ricoeur consisting of naive reading, structural analysis, critical analysis and discussion was applied.

#### Results:

Fracture patients were condemned to make a choice when confronted with the possibility of the early detection of osteoporosis. Many questions regarding prevention of new fractures and prospects in the case of a positive test result were raised. The major themes were related to the consequences of knowing what might be hidden in the bones, and the responsibility to prevent illness.

#### Conclusion:

The confrontation with the potential risk of osteoporosis provokes fear and worry in patients about living a daily life and anxiety about being treated as a sick person, but in return, it motivates patients to adopt a bone-healthy lifestyle. In general, patients prefer to be given knowledge of their bone health status over not knowing, and being able to seek further information on the condition they face.

**Keywords:** Fragility fracture, Osteoporosis, Patient experiences, Phenomenological hermeneutic, Interview, Screening intervention.

### Article History

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## 1. INTRODUCTION

Despite its global dissemination, osteoporosis is an under-diagnosed condition [1 - 5]. This systemic skeletal disease is characterized by low bone mass and microarchitectural deterioration of bone tissue that increases bone fragility and the risk of fractures [6 - 8]. A history of prior fracture is an impor-

tant factor in assessing the risk for future fractures [9], and early detection and treatment of osteoporosis are essential in preventing disability, pain, increased mortality, and other harms associated with fractures. The relevance of targeting patients presenting a fracture is thus clear. An evaluation of the Scottish Fracture Liaison Service (FLS) after eight years [2] showed this coordinator-based, post-fracture model of care to be cost-effective in ensuring that fragility fracture patients receive appropriate assessment and intervention to reduce the risk of future fractures [10]. The documented reduction in

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fracture incidences, including costly and disabling hip fractures, is essential for patients and society.

## 2. BACKGROUND

Convinced by the desirability of FFP and aware of the associated increased number of patients being confronted with a potential diagnosis of osteoporosis, it is worth considering how this affects patients. A Canadian study of osteoporosis patients' perception of their care pathway following a low-energy fracture [11] concluded that, when improving the uptake of osteoporosis testing and care, patients' awareness of their needs should be matched with the delivery of immediate information by a health care professional. While a Danish qualitative study of elderly women's experiences of screening for osteoporosis found no major adverse psychological consequences of screening for osteoporosis, the importance of patients' knowledge of the disease was highlighted [12]. However, based on a study of Danish elderly women's ideas of osteoporosis, Reventlow suggested, that the result of osteoporosis investigation and its cultural interpretation could trigger a reconstruction of the body-self as weak and having reduced capacity [13]. Furthermore, it was suggested that health professionals pay greater attention to people's models and images of risk conditions [14]. Thus, even if screening itself fails to trigger serious adverse psychological effects, the possibility of the discovery of osteoporosis may have consequences for the person's lived life. A Danish study of 65+ year old women's experiences at the time of diagnosis and six months later suggested a need for improving information on osteoporosis and how to live with it [15]. Patients' experiences of living with osteoporosis and their need for health services are well-described especially in elderly women (not necessary fractured) and recently published systematic reviews exist on these topics [16 - 18]. Bombak and Hansson suggest the need for balance between presenting osteoporosis as a serious health condition and producing unwarranted anxiety and inactivity [18]. An impending implementation of a more systematic Fracture Prevention Programme (FFP) in Denmark (where FFP is very sparse yet) may result in an increasing number of male and female middle-age fracture patients being target about osteoporosis screening. Thus, the aim of this study was to investigate male and female fracture patients' awareness of osteoporosis and to explore their experiences when confronted with the choice of being tested for osteoporosis given that their fracture might be a result of reduced bone strength.

## 3. MATERIALS AND METHODS

To study experiences and awareness, the overall framework of this study has a phenomenological hermeneutical approach. The semi-structured interviews were analysed using a Ricoeur-inspired method described by Lindseth and Norberg [19].

### 3.1. Materials

In this study, we wanted to explore the following question: "What is the essence of the choice to be tested for osteoporosis" (= the phenomenon) as experienced by the fracture patient". As the goal of this study was to achieve a deeper

understanding of being in the world with this choice (the phenomenon), conversations with people who have experienced this phenomenon were essential. Inspired by Steinar Kvale's recommendation that researchers "talk to people" when exploring how they understand their world and their lives [20] semi-structured interviews were conducted. The one guiding principle in selecting informants was the informants' experience of the phenomenon. Therefore, the informants for this study were sampled in accordance to a prevalence study; OFELIA [21], where a large cohort of fracture patients at Aarhus University Hospital (AUH) between May 2014 and April 2015 were offered investigation for osteoporosis by Dual Energy X-ray Absorptiometry (DXA) and pharmacological intervention if needed. As an experienced and trained nurse specialist, the Study Coordinator (SC) of OFELIA had individual enrolment conversations concerning fractures, bone strength and bone health with almost 900 potential participants for OFELIA in the mentioned 12-month study period, ending up with 794 participants. In accordance to that conversation, potential candidates for this current study were chosen and asked for their willingness to participate in an interview. All interviews were planned to be conducted by SC in accordance with DXA before the DXA-result was known. An open-questioned interview-guide was performed on the forehand to assist SC, and all interviews were tape-recorded. In the light of the overall framework being phenomenological hermeneutic, the number of informants was set in advance to be between 10 and 20, with the precise number to be determined when information saturation was reached. Phenomenologists tend to rely on in-depth and enriched data rather than the number of participants [22].

The table above is an illustration of in-depth analysis of interviews from fracture patients being offered testing for osteoporosis. The transcript text is analysed in order to reach a deeper understanding from "what is said" (units of meaning) to capture the meaning of "what is spoken about" by grouping units of significance, ending up in sub-themes and main themes.

### 3.2. Data Collection

Purposive sampling of informants was chosen in order to obtain variations of experiences. Diversity in the patients' immediate reactions and their agreement or refusal when invited for osteoporosis testing, as well as sex, age and fracture localisation were sought. Variation is useful in documenting the scope of a phenomenon and identifying important patterns that hold across variations [22]. The informants' choice with respect to the DXA thus had no influence on inclusion in this study. As the purposive, or judgmental, sampling of informants relies on the researcher's knowledge of the population [22], SC sampled participants for this qualitative study.

All interviews were performed between August 2014 and September 2015 and took place either face-to-face immediately after the DXA procedure or over the phone (two interviews), as preferred by the informant. The opening phrase was (as in accordance with the guide): "Tell me your thoughts right after you were asked about osteoporosis testing". This typically led to a conversation about the circumstances of the fracture epi-

**Table 1. Characteristics of five men and ten women interviewed for a study on low-energy fracture patients' experiences when being offered testing for osteoporosis.**

ID	Sex	Age	Location of Fracture	Pro or Con Testing for Osteoporosis	Osteoporosis Revealed by DXA
1	Female	66	Forearm	Pro	Yes
2	Female	39	Elbow	Pro	No
3	Male	45	Wrist	Con but ended up pro	No
4	Female	56	Ankle	Pro	No
5	Female	65	Wrist	Con but ended up pro	Yes
6	Male	59	Knee/lower leg	Pro	No
7	Female	77	Shoulder	Pro	Yes
8	Male	32	Wrist	Con but ended up pro	No
9	Male	71	Lower leg	Pro	No
10	Female	68	Lower leg	Pro	No
11	Female	75	Knee	Pro	Yes
12	Female	51	Hip	Pro	Yes
13	Female	55	Hip bilat.	Pro	Yes
14	Male	59	Upper leg	Pro	Yes
15	Female	52	Shoulder	Con	Unknown (declined)

sode. Being reminded of their concerns about the DXA option, the informants provided narratives about their experiences in the time leading up to the scan (3-6 weeks) or until declining. The interviews were tape-recorded, lasted for 30-45 minutes excluding time for exchanges regarding, for example, fracture problems and further fracture control and transcribed verbatim by SC immediately after each interview. After transcription and reading of the first 13 interviews, SC and Last Authors (LA) agreed that redundancy had been achieved, and decided to stop after the 15<sup>th</sup> interview. Five men and ten women, aged between 39 and 75 years participated (Table 1). None of the approached fragility fracture patients refused the invitation to participate in an interview and this was independent of whether they participated in the osteoporosis prevalence study [20] or not. Some of the informants, who agreed to participate in an interview based on their experiences of refusing DXA, changed their mind for different reasons but outside the context of the on-going study and ended up having a DXA before being interviewed. Therefore only one of the fifteen informants did not have a DXA.

### 3.3. Analysis

The tape-recorded interviews transcribed as text were analysed with a phenomenological hermeneutical method for researching lived experiences. Lindseth and Norberg [19] developed this method with inspiration from Paul Ricoeur's theory of interpretation [23, 24]. The method consists of three steps: a naive reading, a structural analysis, and critical analysis and discussion. In a naive reading that is, free of preconceptions, the text is read and re-read in order to obtain a spontaneous impression and an immediate understanding of the text as a whole. In the structural analysis, the naive reading is validated and adjusted. Lindseth and Norberg argued, that "to understand a text is to follow its movement from sense to references: from what it says, to what it talks about". Thus, a

deeper understanding of the meaning is reached by identifying units of meaning from each interview ("what is said"), and then unfolded as units of significance ("what is spoken about"), resulting in an in-depth description of the meaning; a comprehensive understanding ("what the text speaks about"). These units are then summarized and grouped into subthemes concluded by the identification of main themes. The final critical analysis and discussion explore the main themes in relation to the research aim or question, the context of the study, and relevant literature. The analysis steps are illustrated and described in the findings below.

## 4. FINDINGS

The findings are analysed according to the three steps in the Ricoeur inspired method developed by Lindseth and Norberg [19] as described above.

### 4.1. Naive Reading

The naive reading undertaken by SC and LA unfolded new perspectives in relation to patient experiences on the pathway from suffering a fracture, to receiving information about the association between bone strength and fracture, to opting for or declining the test for osteoporosis. To the informants, the latter seemed to represent a point of no return. Furthermore, they placed great emphasis on gaining sufficient knowledge about bone health to enable themselves and their families to prevent new fractures through a healthier lifestyle. This was reflected in many questions regarding lifestyle, the prevention of new fractures, and medical treatments for osteoporosis and their potential adverse effects.

### 4.2. Structural Analysis

An in-depth analysis was subsequently performed by re-reading the interviews and selecting unique phrases of what is said (units of meaning) in order to reach a deeper understandin-

**Table 2. Examples of different levels in the analyses.**

Units of Meaning (“what is said”)	Units of Significance (“what is spoken about”)	Sub-Themes	Main Themes
<p>“This is my chance to find out; what the heck, if it’s not detected, it will only get worse”. (ID 2)</p> <p>“Now, I don’t know anything about this whether you should eat more calcium or whatever. But if something could be done for the children milk and the like, it’s just to get started.” (ID 4)</p> <p>“Well, but I believe that if I’d said “No, that’s not for me”, I would regret it later ‘what if this or what if that ‘ Now things are going to get cleared up. Had I refused it, I’d never stop wondering if I done the right thing.” (ID 3)</p>	<p>A feeling of relief at being given the opportunity to have the DXA</p> <p>A focused attention on own and family’s bone health. A readiness for information on how to prevent further fractures through a change of lifestyle.</p> <p>The benefits of knowledge are found to be stronger than the benefits of ignorance.</p>	<p>Reasons for being tested</p> <p>Early disease detection</p> <p>Increased concern or a changed behaviour</p> <p>Need for knowledge and fear of consequences</p> <p>Early disease detection</p>	<p>The “obvious” choice</p>
<p>“I might learn to live without football, but perhaps there are other things that I do now that I should stop doing that wouldn’t be fun at all.” (ID 8)</p> <p>“If I hadn’t agreed to being examined, I would worry about it being severe.” (ID 7)</p>	<p>An increased concern imagining a life with osteoporosis as different from a previous lifestyle. Information, especially on the physical aspects of osteoporosis, is requested.</p> <p>The feeling that declining the offer of DXA would be more harmful than the confrontation with a (potentially positive) result.</p>	<p>Increased concern or a changed behaviour</p> <p>Need for knowledge and fear of consequences</p>	<p>Causing worry about illness in healthy people</p>

The table above is an illustration of in-depth analysis of interviews from fracture patients being offered testing for osteoporosis. The transcript text is analysed in order to reach a deeper understanding from "what is said" (units of meaning) to capture the meaning of "what is spoken about" by grouping units of significance, ending up in sub-themes and main themes.

g and to capture units of significance *i.e.* “what is spoken about” for further grouping in themes that capture the essence of the expressed experiences.

In the next level of interpretation (as illustrated in examples Table 2), two major themes were formulated: 1) the “obvious” choice, and 2) causing worry about illness in healthy people.

**4.3. The Critical Analysis/Comprehensive Understanding**

The two themes were now explored in relation to the patients’ experiences on the pathway from opting for or rejecting the examination for osteoporosis. Moreover, the following discussion of the themes included the existing literature.

**4.3.1. The “Obvious” Choice**

When offered a test for osteoporosis, the participants were faced with a dilemma. Some participants were already concerned about their bone health and felt relief at being given the opportunity to have the DXA: “*This is my chance to find out; what the heck, if it’s not detected, it will only get worse* (ID2)”. For others, the choice presented the dilemma of the fear of confronting a positive DXA finding and the curiosity (or even obligation) to know the result. One said, “*I remember wondering what they might end up finding if I decided to take the test* (ID6)”, while another said “*It gives you a chance to receive treatment to prevent or defeat a potential problem, right?* (ID13)”. Several respondents indicated that the choice of the DXA scan was a foregone conclusion for someone faced with a fracture that could be caused by low bone strength: “*It is better to know it, so I don’t mess up, if I do have it* (ID9); *If it turns out that there is something anyway, you know ... you’re lucky to be diagnosed* (ID1)”. The feeling that declines the

offer of DXA would be more harmful than the confrontation with a (potentially positive) result was expressed in various ways: “*The pros of being examined definitely outweigh the cons* (ID3)” and “*If I hadn’t agreed to being examined, I would worry about it being severe*” (ID7). The participants thus found the benefits of knowledge stronger than the benefits of ignorance. The following quotations show that the participants’ choice was influenced by their knowledge that deterioration can be prevented. An elderly woman said: *I thought like if I do have a bone problem, then I’d rather know, so that I might start doing whatever I can do about it, both in terms of how I eat and everything else* (ID4)”. A middle-aged woman said: “*I was delighted that I could be tested so that I would know where I stand that something can be done so that I don’t end up a total cripple* (ID12)”. A man in his thirties said: “*In the end, I thought, if something can be done to prevent it, and I can do something myself after all, I’ll be better off knowing’* (ID8)”.

Many participants were attracted by the opportunity to improve their knowledge about their body and indicated their willingness to make any needed changes in lifestyle and behaviour. They were also eager to know more about the consequences of the disease, and how to act to avoid new fractures.

Many participants shared the perception that osteoporosis is not a life-threatening disease. As a woman suffering from rheumatoid arthritis said: “*You know, you’re not really sick it’s just something that you have* (ID11)”. One informant, suffering from diabetes and a range of comorbidities, found other diseases more threatening, and was unfazed by hearing that he might have osteoporosis (ID14). An elderly participant made it clear that “*No, no, I wasn’t scared. If something can be done, it would be good to know* (ID10)”. Statements like these highlighted the value seen in knowing one’s health status and

the readiness to act accordingly.

Still, some informants imagined a life with osteoporosis as painful and invalidating. One woman was burdened by her knowledge of the severe pain caused by a close friend's osteoporosis (ID5). The participants recognized that their knowledge of osteoporosis was very limited and was founded primarily on images of elderly relatives or acquaintances. Moreover, these participants decided on having the DXA scan and experienced the need for clarification provoked by their fear of the disease.

To illustrate her reasons for rejecting DXA, a woman said "Enough is enough, and No more searching for diseases and interference by experts in my life, which is already affected by other diseases". She felt that too many people had an opinion on her lived life:

"Well, it wasn't that I was scared by osteoporosis it was simply that so many people had already been looking into this my medical record and well, at my life that's what it feels like when you are caught up here, doesn't it?"

She continued:

"Yes, I believe it can be summed up in one word and that's insecurity. Uneasiness/insecurity about what this will lead to. It's more than enough It's just that it gets too much kind of too many words and too much interference. That's my way of thinking" (ID15).

It appears that this informant's rejection of the test was not related to the condition per se, but applied to her life in general, which she felt had been "taken over" by medical professionals.

#### 4.3.2. *Causing Worry About Illness in Healthy People*

In weighing up the consequences of investigation, the informants considered the impact of a positive result on their quality of life. They were aware of both potential harms and benefits of ignorance of "what is lying undiscovered in the bones". One informant described his worries about his status with his insurance company: "But suppose they found something? Then [the insurers] could take their precautions, or say 'We don't want you as our customer anymore', and where could I take out health insurance, then? (ID3)". Knowing one's state of health was seen to involve disadvantages, and knowledge of the consequences could be imagined as a fear of being ill and left with many diseases. An old woman described the dilemma between knowledge and ignorance in saying that she might live the rest of her life happily: *What you don't know won't hurt you* (ID7). A middle-aged man formulated the insight in this way: *Healthy people being suddenly confronted with a potential disease interfering with their well-lived life* (ID 6). A younger man spoke of being given a sickness profile: "That's the disadvantage of saying yes to the investigation you'll be seen as sick, at least in the time when the suspicion lingers (ID 8)". Feelings of anxiety and uncertainty caused by the prospect of an osteoporosis diagnosis

were also mentioned as the price of deciding on the test.

Some of the informants confidently accepted the scan with no uncertainty about their good health and were as a result totally unprepared for osteoporosis diagnosis. They had considered their body as generally strong and saw the fracture as a result of an unlucky incident. One said "Otherwise, I think that I have a fantastic way of life. I've always felt strong as a horse so I said to myself, no problem with [accepting DXA], because I certainly haven't got that [osteoporosis] (ID1)". A woman, who had what health professionals consider a low-energy slip, saw it as a serious fall, and admitted: "Well, I was 100% convinced that I didn't have osteoporosis. You know, that is something that old people get. I was convinced that with the fall that I had, my hip was bound to break in any case (ID12)". Lack of concern was also reflected in an elderly man's remark that "All knowledge is good knowledge (ID9)". To others, the confrontation with the prospect of having fragile bones in addition to the fracture focused their attention on their own and their family's bone health. Their readiness for information on how to prevent further fractures through a change of lifestyle was expressed in various ways: *Well, I have no idea if I need to eat more calcium or whatever. But if something can be done, then you just have to get started* (ID 4). This awareness seemed to motivate the participants' ambition to stay healthy. They described their ideas for activities to get started on: "If going for a run once a week will make a world of difference well then, of course I'd do that (ID3); My sister does these five Tibetans [yoga] each morning, and I'm going to do that, too (ID1)". The participants' descriptions indicated that they saw a life with osteoporosis as a departure from their previous lifestyle, and they requested information, especially on the physical aspects of osteoporosis: "I might learn to live without football, but perhaps there are other things that you do now that you should stop doing that wouldn't be fun at all (ID8)". Patients' awareness of the hereditary factors in the course of osteoporosis was revealed in concern for their children's lifestyle, reaching beyond their young children. In the participants' view, no one should assume that they were exempt from risk. It was understood that otherwise healthy children might have an undetected illness. Healthy behaviour regarding bone strength was strongly recommended and responsiveness to advice on preventing illness was evident, not only in relation to the patients themselves, but also in relation to their families. An elderly woman thus described her plan to talk to her middle aged daughter about taking calcium to prevent osteoporosis: *Surely, she might just as well start now* (ID7).

To sum up our comprehensive understanding of the two themes:

- [1] When informed about the link between fracture and bone health, the choice of being investigated for osteoporosis was obvious for a majority of the participants, and they found that the benefits of knowing about bone health status were stronger than not knowing.
- [2] Causing worry about illness in healthy people turned out as a concern about the consequences of knowing what is hidden in the bones, and as a responsibility to

prevent illness if possible.

## 5. DISCUSSION

We observed that the awareness of a connection between bone health and fracture risk aroused participants' curiosity and sense of responsibility for knowing their bone health status. This is reflected in the observation that when approaching fragility fracture patients for enrollment in the osteoporosis prevalence study [21], only 62 of more than 800 potential participants declined participation and DXA. The informants expected that rejecting DXA would be more harmful than confronting the knowledge of their bone health status. This in line with the findings of a review of patients' reasons for declining or accepting participation in cardiovascular health check-ups in which it was concluded that gaining information, or the mere option of gaining information, increases the sense of responsibility [25]. That study also found that the awareness that one's health can be improved forces a choice between acting or not acting, and subsequently the responsibility for the consequences of this choice [25]. Of the "act of choosing", the Spanish philosopher Savater states that, once offered a choice, the individual is forced to make a decision, and that the opportunity not to be asked to choose no longer exists, thus making the dilemma posed by the choice inescapable [26]. Drawing on Sartre, Savater argues that being given a choice is to be condemned to be free. This is not unlimited freedom; the choice must be made from among the given options and rests on a combination of knowledge, perception, and decision-making in confrontation with the given options. Together, these three elements are inevitable if the choice is to be seen as voluntary [26].

In the context of the present study, the participants had no opportunity to not know, or to remain oblivious of the already presented information (the connection between bone strength and fracture risk), and neither could they escape the choice. Philosophically speaking, the situation "condemned" the patient to choose between accepting and declining investigation. In the absence of the three elements of a voluntary choice, the autonomy of the patient is challenged. A lack of knowledge, unrealistic fear, and imaginations of life with osteoporosis could support arguments for the benefits associated with a paternalistic or authoritarian style of health provision.

While waiting for confirmation or rejection of the diagnosis of osteoporosis, some informants experienced anxiety, insecurity and, a sense of being treated as if they were sick. Such feelings are not unusual, as shown by Rothmann (2014) in particular, the lack of knowledge of the consequences of screening for osteoporosis caused concern [12]. Svensson *et al.*, found that fear and concern are a major part of daily life in older women living with osteoporotic vertebral fracture [27]. Hvas *et al.*, discussed, that awareness of osteoporosis in postmenopausal women caused a feeling of uncertainty and worry in some women, and that only women reacting in this way seemed to act in order to prevent future fractures [28]. Thus, the confrontation with a risk of osteoporosis provoked concern about their lived daily life in the informants in this present study as well. This raised questions about the impact of

an osteoporosis diagnosis; unsurprisingly, the level of concern varied according to the patients' condition of life while some of the younger participants expressed concern about the prospects of continuing their very active sports activities, those who were parents, worried about nutrition and their children's health behaviour. Concern about their continued well-being in everyday life was typical of the older women, who were prepared to lead a more physically active lifestyle but could not suppress worries about a life with a disability and severe pain, typically brought on by comparison with their older family members. The WHO recommends [29] screening programmes as a step towards treating previously undetected diseases and avoiding harm to such persons not in need of treatment [30] suggesting an acceptance that individuals are different, and that some prefer knowing about a preventable disease while others prefer being oblivious of potential disease from a fear that the knowledge may compromise their quality of life. In line with the findings of other studies, all informants sought knowledge about osteoporosis and its consequences, and how new fractures can be prevented by a bone healthy lifestyle. In the study by Rothmann *et al.*, participants with limited knowledge of osteoporosis requested more information when faced with a screening programme [12]. Likewise, Beaton found that patients entering a fracture liaison programme needed immediate and clear information [11]. As suggested by Luc *et al.*, [31], a coordinated support system through an FLS-coordinator can make a difference in enhancing participants' engagement in their own care.

In line with earlier studies [11, 12], some informants expect osteoporosis to be a painful and life shortening disease, while others see it as relatively benign. The participants in the present study were generally very action oriented in adopting a healthy lifestyle in order to prevent fractures and to stay healthy. Confidence in their ability to take action and improve their health to prevent further fractures seemed to be a significant factor in their acceptance of screening. The insecurity brought on by the waiting time for the DXA seemed to be of minor importance when they assessed the gain by knowing of bone health status. Similarly, Beaton *et al.*, found that when patients understood the connection between fracture and bone health, they produced an action oriented appraisal of what to do to reduce the risk of further bone fracture [11]. For some of our informants, the decision to submit to the scan was based on confidence in their good health and that their lifestyle was healthy. Other studies have reported similar findings [13, 25]; the former thus describe "the value of peace of mind" shared by both participants and nonparticipants, meaning that participants accept the test in order to reduce fear and be reassured of their good health status, while nonparticipants' refrain from taking the test to avoid anxiety about the possible outcomes.

Some informants mentioned their concern about breaches of confidentiality in relation to the outcome of the DXA and their uncertainty about the impact of the results on their general health care and insurance needs. These findings corroborate with other studies [25] which found that such uncertainties led participants to decline participation. We interpreted this as a natural concern in a world with computerized medical records and a lack of transparency in what is private and what is public

data. This highlights the need for a health system with convincing credibility in the storage of sensitive data.

### 5.1. Methodological Strengths and Limitations

While writing the article, the Standards for Reporting Qualitative Research SRQR and COREQ were followed to ensure trustworthiness, transparency and reliability. The purposive sampling at a time where nobody knew the result of the DXA and without any forehand preferred reaction, age or gender from other, underlined the transferability of a representative sample. The objective translation of the audio-taped interviews literally word by word underlined the reliability in the data. In the structural analysis, the presentation of the exact spoken words (cites) and the transparency in the interpretations of what actually “was told” gave trustworthiness to follow all steps in the in-depth analysis and credibility to the conclusions drawn [22].

Using individual interviews to explore the experiences of patients when they were offered the choice of being tested for osteoporosis is the appropriate method for studying patients’ experiences [22]. Yet, the sampling of informants was somewhat challenging: while searching for a wide range of informants according to age, fracture location, and sex was straight-forward, we nearly failed including patients both pros and cons testing. Only one out of 15 informants sampled in the end not want investigation despite a conversation given words to the full acceptance of both being informant in this study and refusing testing in OFELIA. In sampling informants, 3-4 individuals were chosen from the expectation that they would refuse to be tested. However, all but one of the approached patients ended up being tested. With the knowledge gained from analysing the interviews, it is clear that patients who have been made aware of the connection between fracture and bone health will almost invariably accept the offer of testing. On the other hand, the strength of this study is the large size of the source group from which the first author made a purposeful sampling of informants.

### 5.2. Perspectives

Keeping aside the socioeconomic considerations, we recommend that a fracture prevention programme includes a thorough consideration of the personal costs of early detection of osteoporosis in fracture patients. Healthcare professionals in this program plays an important role and should be prepared for the patient’s; need for immediate advice and an answer to questions regarding, for example, the prevention of new fractures, a healthy bone lifestyle, the consequences of being diagnosed with osteoporosis, the consequences of declining DXA, and transparency in the management of the DXA results.

We suggest that in depth information on the test and an explanation of the connection between bone health and bone fracture should be given in dialogue, thus providing an opportunity for further questions. Direct access to written and electronic patient information and instructions is crucial. Although patients should be challenged when they reject osteoporosis investigation, tolerance and acceptance of fracture patients’ choice are recommended.

### CONCLUSION

When a person who has suffered a fracture is confronted with the option of a test for early detection of underlying osteoporosis, the patient is “condemned” to make a choice. Knowledge of the connection between fracture and bone health leaves no option of evading the choice. A large majority of patients prefer to be given knowledge of their bone health status over not knowing, and seek further information on the condition facing them.

The confrontation with the potential risk of osteoporosis provokes fear and worry in the patient about her/his daily life and anxiety about being treated as a sick person, but in return, it motivates patients to adopt a bone-healthy lifestyle.

### ETHICS APPROVAL AND CONSENT TO PARTICIPATE

The Regional Ethics Review Board was asked to evaluate and approve the study, but declared, that since the study was non interventional, approval and obtaining informed consent were not needed. The study was approved by the Danish Data Protection Agency (J.no. 2007-58-0016).

### HUMAN AND ANIMAL RIGHTS

No animals/humans were used for studies that are the basis of this research.

### CONSENT FOR PUBLICATION

The informants were given oral and written information about the study, and the verbal consent was obtained. All informants were repeatedly assured that they could withdraw their participation at any time before or during the interview without any consequences for any further treatment or their participation in OFELIA.

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### CONFLICT OF INTEREST

The authors declare no conflict of interest, financial or otherwise.

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Authors' contributions: RT, BL, OB and PD designed the study, RT and PD performed the study and collected data, RT and PD analyzed data, BL and OB contributed important reagents, RT, PD and BL wrote paper.

## REFERENCES

- [1] Ganda K, Puech M, Chen JS, *et al.* Models of care for the secondary prevention of osteoporotic fractures: a systematic review and meta-analysis. *Osteoporos Int* 2013; 24(2): 393-406. [http://dx.doi.org/10.1007/s00198-012-2090-y] [PMID: 2282 9395]
- [2] McLellan AR, Wolowacz SE, Zimovetz EA, *et al.* Fracture liaison services for the evaluation and management of patients with osteoporotic fracture: A cost-effectiveness evaluation based on data collected over 8 years of service provision. *Osteoporos Int* 2011; 22(7): 2083-98. [http://dx.doi.org/10.1007/s00198-011-1534-0] [PMID: 2160 7809]
- [3] Mehrpour SR, Aghamirsalim MR, Sorbi R. Are hospitalized patients with fragile fractures managed properly in relation to underlying osteoporosis? *J Clin Rheumatol* 2012; 18(3): 122-4. [http://dx.doi.org/10.1097/RHU.0b013e31824ee8af] [PMID: 22426584]
- [4] Giangregorio L, Papaioannou A, Cranney A, Zytaruk N, Adachi JD. Fragility fractures and the osteoporosis care gap: An international phenomenon. *Semin Arthritis Rheum* 2006; 35(5): 293-305. [http://dx.doi.org/10.1016/j.semarthrit.2005.11.001] [PMID: 16616152]
- [5] Elliot-Gibson V, Bogoch ER, Jamal SA, Beaton DE. Practice patterns in the diagnosis and treatment of osteoporosis after a fragility fracture: A systematic review. *Osteoporos Int* 2004; 15(10): 767-78. [http://dx.doi.org/10.1007/s00198-004-1675-5] [PMID: 1525 8724]
- [6] Consensus development conference: Diagnosis, prophylaxis, and treatment of osteoporosis. *Am J Med* 1993; 94(6): 646-50.
- [7] Center J, Eisman J. The epidemiology and pathogenesis of osteoporosis. *Baillieres Clin Endocrinol Metabol* 1997; 11(1): 23-62. [http://dx.doi.org/10.1016/S0950-351X(97)80489-2]
- [8] Kanis JA. Diagnosis of osteoporosis and assessment of fracture risk. *Lancet* 2002; 61;359(9321): 1929-36. [http://dx.doi.org/10.1016/S0140-6736(02)08761-5]
- [9] Klotzbuecher CM, Ross PD, Landsman PB, Abbott TA III, Berger M. Patients with prior fractures have an increased risk of future fractures: A summary of the literature and statistical synthesis. *J Bone Miner Res* 2000; 15(4): 721-39. [http://dx.doi.org/10.1359/jbmr.2000.15.4.721] [PMID: 1078 0864]
- [10] McLellan AR, Gallacher SJ, Fraser M, McQuillan C. The fracture liaison service: Success of a program for the evaluation and management of patients with osteoporotic fracture. *Osteoporos Int* 2003; 14(12): 1028-34. [http://dx.doi.org/10.1007/s00198-003-1507-z] [PMID: 1460 0804]
- [11] Beaton DE, Sujic R, McLroy Beaton K, Sale J, Elliot-Gibson V, Bogoch ER. Patient perceptions of the path to osteoporosis care following a fragility fracture. *Qual Health Res* 2012; 22(12): 1647-58. [http://dx.doi.org/10.1177/1049732312457467] [PMID: 2292 3385]
- [12] Rothmann MJ, Huniche L, Ammentorp J, Barkmann R, Glüer CC, Hermann AP. Women's perspectives and experiences on screening for osteoporosis (Risk-stratified Osteoporosis Strategy Evaluation, ROSE). *Arch Osteoporos* 2014; 9(1): 192. [http://dx.doi.org/10.1007/s11657-014-0192-1] [PMID: 2513 4980]
- [13] Reventlow SD, Hvas L, Malterud K. Making the invisible body visible. Bone scans, osteoporosis and women's bodily experiences. *Soc Sci Med* 2006; 6; 62(11): 2720-31.
- [14] Reventlow S, Bang H. Brittle bones: Ageing or threat of disease exploring women's cultural models of osteoporosis. *Scand J Public Health* 2006; 34(3): 320-6. [PMID: 16754591]
- [15] Hansen C, Konradsen H, Abrahamson B, Pedersen BD. Women's experiences of their osteoporosis diagnosis at the time of diagnosis and 6 months later: A phenomenological hermeneutic study. *Int J Qual Stud Health Well-being* 2014; 9: 22438. [http://dx.doi.org/10.3402/qhw.v9.22438] [PMID: 24559545]
- [16] Barker KL, Toye F, Lowe CJM. A qualitative systematic review of patients' experience of osteoporosis using meta-ethnography. *Arch Osteoporos* 2016; 11(1): 33. [http://dx.doi.org/10.1007/s11657-016-0286-z] [PMID: 2773 9032]
- [17] Chou L, Shamdasani P, Briggs AM, *et al.* Systematic scoping review of patients' perceived needs of health services for osteoporosis. *Osteoporos Int* 2017; 28(11): 3077-98. [http://dx.doi.org/10.1007/s00198-017-4167-0] [PMID: 2876 2126]
- [18] Bombak AE, Hanson HM. Qualitative Insights from the Osteoporosis Research: A Narrative Review of the Literature. *J Osteoporos* 2016; 2016: 7915041. [http://dx.doi.org/10.1155/2016/7915041] [PMID: 27994908]
- [19] Lindseth A, Norberg A. A phenomenological hermeneutical method for researching lived experience. *Scand J Caring Sci* 2004; 18(2): 145-53. [http://dx.doi.org/10.1111/j.1471-6712.2004.00258.x] [PMID: 15147477]
- [20] Kvale S. The Qualitative Research Interview. *J Phenomenological Psychol* 1983; 14(1-2): 171-96. [http://dx.doi.org/10.1163/156916283X00090]
- [21] Tei RMH, Ramlau-Hansen CH, Plana-Ripoll O, Brink O, Langdahl BL. OFELIA: Prevalence of Osteoporosis in Fragility Fracture Patients. *Calcif Tissue Int* 2018; 1-13. [PMID: 30225727]
- [22] Polit DF, Beck CT. *Essentials of nursing research : Appraising evidence for nursing practice.* 7. Philadelphia: Wolters Kluwer Health/Lippincott Williams & Wilkins 2010.
- [23] Ricoeur P. *Interpretation theory: Discourse and the surplus of meaning* 8 pr. Fort Worth: Texas Christian University Press 1976.
- [24] Dreyer PS, Pedersen BD. Distanciation in Ricoeur's theory of interpretation: Narrations in a study of life experiences of living with chronic illness and home mechanical ventilation. *Nurs Inq* 2009; 16(1): 64-73. [http://dx.doi.org/10.1111/j.1440-1800.2009.00433.x] [PMID: 19228305]
- [25] Stol Y, Asscher E, Schermer M. Reasons to Participate or not to Participate in Cardiovascular Health Checks: A Review of the Literature. 2015; (20): 1-11.
- [26] Savater F. [El valor de elegir 2003 Fernando Savater Editor Ariel, SA, Barcelona] (A Rosenlund Trans) Mod til at vælge. 2005. 1th ed.
- [27] Svensson HK, Olofsson EH, Karlsson J, Hansson T, Olsson LE. A painful, never ending story: Older women's experiences of living with an osteoporotic vertebral compression fracture. *Osteoporos Int* 2016; 27(5): 1729-36. [http://dx.doi.org/10.1007/s00198-015-3445-y] [PMID: 2665 9067]
- [28] Hvas L, Reventlow S, Jensen HL, Malterud K. Awareness of risk of osteoporosis may cause uncertainty and worry in menopausal women. *Scand J Public Health* 2005; 33(3): 203-7. [http://dx.doi.org/10.1080/14034940510005716] [PMID: 1604 0461]
- [29] Wilson JMG, Jungner G. *Principles and practice of screening for disease.* 7. Geneva (tr. France): World Health Organization 1968.
- [30] Andermann A, Blancaert I, Beauchamp S, Déry V. Revisiting Wilson and Jungner in the genomic age: A review of screening criteria over the past 40 years. *Bull World Health Organ* 2008; 86(4): 317-9. [http://dx.doi.org/10.2471/BLT.07.050112] [PMID: 18438522]
- [31] Luc M, Corriveau H, Boire G, Filiatrault J, Beaulieu MC, Gaboury I. Patient-Related Factors Associated with Adherence to Recommendations Made by a Fracture Liaison Service: A Mixed-Method Prospective Study. *Int J Environ Res Public Health* 2018; 15(5): 944. [http://dx.doi.org/10.3390/ijerph15050944] [PMID: 29747415]