Chronic Conditions and Menopause

Left in limbo – Experiences and needs among postmenopausal women newly diagnosed with osteoporosis without preceding osteoporotic fractures: A qualitative study

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Abstract
Introduction: Despite the fact that the first osteoporotic fracture is preventable, osteoporosis is still a major health challenge. The disease is highly prevalent among postmenopausal women. However little is known about how to meet and support women, when they are diagnosed with osteoporosis without preceding fractures. Therefore this study aims at gaining a deeper understanding of how women experience being diagnosed. Furthermore to describe and identify their needs, which should be met in future healthcare services.

Methods: We conducted a phenomenological qualitative study. We included 17 women aged 52–65 and collected data through semi-structured interviews. We analysed data following Giorgi’s methodology.

Findings: Needs among the women were classified into three main themes: (1) needs of targeted and tailored information about osteoporosis, (2) needs of being prepared for GP visit to participate in treatment decision-making and (3) needs of being able to take care of bone health.

Conclusion and implications: In general the women experienced as being left ‘in limbo’, and they requested targeted and tailored information about osteoporosis. In particular, they want information about dual-energy X-ray absorptiometry (DXA) scan results and treatment options in advance of the GP visit. This will help them in being prepared and able to participate in treatment decisions. They ask for support in self-management of the disease with less focus on disease and risk of fracture. Instead, they demand more attention on the benefits of detecting early stage osteoporosis. The study highlights the call for new approaches to postmenopausal women newly diagnosed with osteoporosis without preceding fractures.

Keywords
Experiences, needs, osteoporosis, postmenopause, qualitative study

Introduction
Identifying and treating patients at risk of osteoporotic fractures could reduce the long-term burden of osteoporosis since the first fracture is associated with an

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increased risk of further fracture.\textsuperscript{1–5} This is highly relevant among postmenopausal women given that osteoporosis is estimated to afflict 40.8\% of European women over the age of 50 years of whom one in three is predicted to have a fracture during their lifespan.\textsuperscript{2,6} However, research has shown that information on bone density results and the associated fracture risk can cause increased concern and insecurity in women.\textsuperscript{7–9} Other studies report similar findings and emphasize that women being diagnosed at an early stage of osteoporosis have difficulties in interpreting the diagnosis and the risk of fracture, and in managing everyday life with osteoporosis.\textsuperscript{10–13} Furthermore, Nielsen et al. conclude that healthcare professionals need to consider what is important and meaningful for patients when they suggest how patients should handle osteoporosis.\textsuperscript{14}

A recently published qualitative systematic review of patients’ experience of osteoporosis concludes that a need remains to adjust healthcare professionals’ interactions with patients. Healthcare professionals must to a greater extent be able to understand how patients can be better helped to receive and understand their osteoporosis diagnosis.\textsuperscript{15} In addition a Danish qualitative study indicates a need for improved support for women when they are prescribed anti-osteoporotic treatment without having experienced an osteoporotic fracture.\textsuperscript{16}

Despite the increased prevalence of osteoporosis and the above-mentioned challenges, very few studies have focused on postmenopausal women when being diagnosed with osteoporosis without preceding fractures. Therefore this study aims at gaining a deeper understanding of how those women experience being diagnosed with osteoporosis. The focus is on describing and identifying their needs, to find out how we should design and develop future healthcare services to promote optimal osteoporosis management.

**Materials and methods**

**Design**

We conducted a phenomenological qualitative study.

**Data collection and participants**

Women were consecutively invited to participate by the laboratory specialist conducting DXA scans at a Danish University Hospital between May and August 2015. Those who agreed to participate were given an information letter about the study and what participation involved. The women were contacted by phone by the first author within a few days after the general practitioner (GP) gave them the result of the DXA and treatment was decided. They were given further information verbally before they decided whether they would like to participate or not. Inclusion criteria were a T-score below $-2.5$ (lower back or hip) confirmed by a DXA scan, age 50–65 years, no previous known osteoporotic fractures and at least one of the known risk factors for osteoporosis. Exclusion criteria were a previous diagnosis of osteoporosis, or a diagnosis of severe mental disorders such as dementia or severe depression, which could influence the women’s ability to participate in the interviews.

The study consisted of semi-structured interviews using an interview guide as recommended by Kvale and Brinkmann.\textsuperscript{17} The women were interviewed in their homes. An open and active approach was employed as recommended in phenomenology.\textsuperscript{18} The interviews lasted 75 min on average. The interviews were recorded and transcribed verbatim.

**Data analysis**

The analysis was guided by Giorgi’s methodology in four steps.\textsuperscript{19} Initially the complete transcribed interviews were read several times to get an overall impression of the material and identify themes. The material was then divided into smaller meaningful units after which codes and subgroups were identified based on the meaningful units. The final step was to identify overall themes describing the essence of the women’s experiences where the identified main categories were subject to a more general description and discussion of the experiences and expressed needs (Table 1).

In order to enhance validation, all authors were involved in the process of analysis.\textsuperscript{17}

**Findings**

Seventeen women met the inclusion criteria and they all agreed to participate. Ages ranged from 52 to 65 years. For description of participant characteristics see Table 2.

Through the analysis, experiences and needs among women when diagnosed with osteoporosis were categorized into three main themes: (1) needs of targeted and tailored information about osteoporosis, (2) needs of being prepared for GP visit to participate in treatment decision-making and (3) needs of being able to take care of bone health.

(1) Needs of targeted and tailored information about osteoporosis

The women had a DXA scan at the hospital either because they requested it from their GP due to a known family history of osteoporosis ($n=8$), or the GP ordered it due to the presence of risk factors for
The nine women being referred to a DXA scan were in general more surprised and worried since they have not paid any attention to the disease.

'I was a bit surprised when my doctor told me that she would like to send me to a DXA scan. I have not paid any attention to osteoporosis since I'm not that old' (W4)

Due to the lack of attention of osteoporosis in their everyday lives, the women often had little knowledge about the disease. Therefore, many of them reported that they searched the Internet for information about osteoporosis. Mostly, it was the nine women, who were referred to a DXA scan by the GP, who expressed the need for more information about osteoporosis immediately after the scan. However, since they did not know whether they had the disease or not, they found it challenging to find relevant information. One of the participants, a 54-aged woman without known familiar osteoporosis, expressed:

'When I got home from the scan I ’googled’ osteoporosis. Most of the hits were about risk of fractures. I felt sickened and since I really didn’t think that I had the disease I stopped reading about it' (W10)

The eight women, who requested a scan, were more prepared for being diagnosed. Due to the prevalence of osteoporosis in their family, they had sufficient fundamental knowledge about the disease. However, those women expressed that they found it difficult to interpret the diagnosis when being diagnosed without preceding fractures. In particular, they were in doubt about the severity of the disease. Overall, the women expressed that most of the information found, when searching the Internet was difficult to interpret, and they doubted the relevance in relation to their own situation. They

osteoporosis (n = 9). The women asking for a scan expressed that they had some concerns about the risk of ending up like family members who often suffered from severe fragility fractures as this woman explained.

'I asked my doctor for a DXA scan since my grandmother, my mother, and my sister have had osteoporotic fractures. So I have some bad odds, and I would really like to do the best I can to prevent not ending up like them' (W6)
described that most of the information focused on osteoporosis as a serious disease and the increased risk of fractures. Therefore many of them stopped reading about osteoporosis since they felt uncertain and anxious instead of better informed.

(2) Needs of being prepared for GP visit to participate in treatment decision-making

In Denmark the result of the DXA scan and treatment recommendations are described and sent from the hospital to the GP. This is shared with the women during a GP visit. Some women felt that being given the result of the DXA scan and subsequent diagnosis this way puts them in a sick-role unnecessarily:

‘Since it’s not a serious disease, it could be relevant to get the result of the scan in advance. That could demystify what is wrong with me, and it would be easier for me to talk to the GP about treatment options’ (W12)

In general most of the women felt that they were not prepared for the GP visit. Being unprepared meant that they did not have the knowledge necessary to understand what the diagnosis meant to them, or what the potential consequences were. They would have liked more information about the disease and treatment options in advance, so they could ask informed questions and participate in treatment decisions.

‘If I have had the opportunity to be more prepared about having osteoporosis and treatment options, then we could have had a dialogue. I had psyched myself up that my bones were fine and wasn’t prepared at all for the consultation’ (W17)

Overall the women agreed on the good fortune of being diagnosed prior to developing a fracture and to start taking steps to prevent it. This is described by this woman who and first was shocked when the GP told her that she had osteoporosis, since her mother and sister had had severe fractures due to the disease. But then later she reflected on the positive aspects of early detection of the disease before a fracture has occurred:

‘When my GP told me that I have osteoporosis I got worried and was thinking of my bones crumbling away. But then I thought that it was good it was detected and that the treatment will prevent fractures’ (W1)

In general, the women experienced that the GP mentioned medication as the only possible treatment. For some women this was fine since she trusted in her GP and his/her opinion of which treatment should be initiated.

‘After I got the diagnosis there was a lot of information during the consultation. My doctor told me that I should start medical treatment, and so I did because I listen to her. I think it’s fine since the medicine should have an effect’ (W1)

However, for some of the other women it was associated with discomfort since they were not able to express concerns about side effects during the consultation. Therefore, they had a lot of thoughts of what to do when they were back home. Additionally they were in doubt of how they could have a dialogue with the GP about the situation:

‘I’m really concerned about those pills and the side effects. So I do not take them, but I’m afraid of telling my doctor. I could just have told him that I didn’t want it, but I was not able to do that’ (W10)

(3) Needs of being able to take care of bone health

The women had, in general, reflections about how to promote bone health in their daily life after being diagnosed. They had concerns about ‘doing the right thing’ in managing the diagnosis. However, they did not discuss this with the GP. Thus they did not know where to obtain valid and evidence based information about lifestyle approaches to promote bone health.

‘I need guidance in bone-healthy lifestyle. What is it actually and how do I do? I do not know whom to ask, since I have declined the medication. I don’t think that the GP or the hospital could help me with lifestyle advices’ (W17)

Overall, the women expressed a great many unmet needs in relation to life with osteoporosis. They all sought more help in managing the disease in their daily life, but were unsure of what the appropriate resources were. For instance, they were unsure how to exercise, since they were afraid of straining their bones due to the increased risk of fractures. They asked for tailored exercise programmes with focus on strengthening the bones. They experienced differing and confusing information about lifestyle approaches to promote bone health when they searched the Internet or asked family and friends. Some described this as being left in limbo, others like a no man’s land.

‘I feel like I’m in no man’s land. It is difficult to find out what I can expect and whom to ask as an osteoporosis patient at my age’ (W16)
Discussion

In general the women requested targeted and tailored information about osteoporosis since they had difficulties in interpreting the diagnosis when no fractures had occurred. Additionally they expressed that they needed to be better prepared for the GP visit. The need for information and preparation differed according to how they experienced diagnosis. Most of the women who had family members suffering from osteoporosis were more concerned about the consequences of having osteoporosis. This is in line with findings in Nielsen et al.’s study. They found that patients with close relatives suffering from severe osteoporosis seemed to be more vulnerable and more worried when they were diagnosed with osteoporosis. They also found that patients’ needs for information about osteoporosis varied significantly. Patients who had not suffered any fractures felt that it was difficult and frightening not knowing how easily a fracture could occur.14 Bombak and Hanson emphasize the need for balance between presenting osteoporosis as a serious health condition and producing unwarranted anxiety and inactivity among patients when being diagnosed.20 Similarly, Salter et al. argue in their study of older women’s experience of osteoporosis screening that screening for osteoporosis and assessment of fracture risk can be understood as a process of biomedicalisation of aging and bone health. They found that women being diagnosed with asymptomatic osteoporosis and thereby informed about the risk of fractures get an illness experience.21 Likewise, we found that the information given should primarily focus on the benefits of detecting early stage osteoporosis and promotion of bone health instead of osteoporosis as a chronic disease and the increased risk of fractures. Otherwise the women feel as though they are being placed in a sick-role unnecessarily.

It is well known that despite the high efficacy of current treatments in the field of osteoporosis poor adherence is a significant problem.22 One large Danish study found that 38.7% of women newly diagnosed with osteoporosis stopped pharmacological treatment primarily due to concerns about negative side effects.23 In our study, the women expressed similar concerns. Some women actually considered the medication as harmful and they had ambivalence regarding following the prescribed treatment. However, most of the women felt that it was difficult to express this during the GP visit since they were not prepared for being diagnosed. Salter et al. have investigated adherence to bisphosphonate medications for the prevention of osteoporosis among older women.24 In their study, they found that adherence to preventive medication for osteoporosis is complex and multifaceted. They claim that within this complex context each patient and their doctor has to make individual decisions as to whether a risk factor should be prioritised or treated once osteoporosis is detected. Salter et al. found that problems of understanding osteoporosis risk and how to manage the disease affect adherence negatively.24 Likewise, our study shows that the women requested targeted and tailored information about osteoporosis and ways of managing the disease to achieve a better understanding of the disease before the GP visit. Furthermore, the women would like to be provided with the DXA scan result beforehand, to be able to better prepare for the treatment decision-making. Both the study of Salter et al. and our study suggest that the women could benefit from being better prepared for the GP visit to pay attention to individual needs in management of the disease.

The women in our study ask for additional support in how to manage the disease with focus on exercise, diet and calcium supplements. However, it was difficult to obtain evidence-based recommendations regarding lifestyle since the GP did not pay much attention to this. Therefore, they started searching for valid information on the Internet about how to promote bone health. When searching for information, they described it as challenging to find out what was ‘the right thing to do’. When asking family and friends they were given different recommendations. Likewise, Sale et al. described how patients in their study spoke about strategies to manage their bone health. They found that their participants followed recommendations from a variety of sources including healthcare professionals, family and friends as well as the media and Internet.25

Our findings are an example of how today’s patients would like to be involved in the process of being diagnosed and prepared for the GP visit to be able to participate in treatment decision-making. The increasing prevalence of people living with long-term conditions and their needs for being engaged and involved requires redesign of health care services. Richards, Coulter and Wicks claim that it is time to deliver patient centred care.26 Eaton et al. highlight new approaches and state that it is of great importance to involve patients in the treatment decision-making process if self-management should be achieved.27 Studies have shown that self-management interventions among patients with chronic diseases help people to manage their disease and face the challenges created by the chronic diseases.28–30 Our study indicates that there is a need for increased focus on the women’s needs in treatment decision-making, and support in self-management of osteoporosis in daily life. As with many other patients with chronic conditions, the women participating in our study are already in charge of their own health, thus they request support in management of the disease in a number of
individual ways. Frosch claims that it is of great importance to develop the science of care and support patient centred care if self-management of chronic conditions is to be improved.31 Coulter et al. argue that tailored support reduces dependency and promote self-management.32 Our study highlights the importance of developing new ways of delivering care for women being diagnosed with osteoporosis without preceding fractures with a focus on keeping the burden of treatment as low and ‘minimally disruptive’ as possible as suggested by Hibbard and Greene.33

Our study has some limitations. Firstly, our findings are context-specific given that diagnostic pathways for osteoporosis may vary from hospital to hospital. In our study, women were recruited from a single University Hospital in Denmark with an established pathway to manage referrals for a DXA scan from their GP. In this case, the expressed needs in the women regarding targeted and tailored information may be a result of this local pathway. Secondly, the interviewer was a health professional. This may have influenced the interviews. For some women it helped to build confidence and they felt that by participating in a research project, they had the opportunity to gain a better understanding of osteoporosis. However, we cannot exclude the possibility that some women modified their statements to please the healthcare professional who conducted the interviews. The high degree of willingness to participate could be a sign of the needs of information among the women. Several women expressed that they were glad that they have participated in the project since they have gained a better understanding of osteoporosis. For some women it helped to build confidence and they felt that by participating in a research project, they had the opportunity to gain a better understanding of osteoporosis. However, we cannot exclude the possibility that some women modified their statements to please the healthcare professional who conducted the interviews. The high degree of willingness to participate could be a sign of the needs of information among the women. Several women expressed that they were glad that they have participated in the project since they have gained a better understanding of osteoporosis.

The semi-structured individual interviews were found to be appropriate since it gave the opportunity to explore individual perspective in depth. We invited women consecutively and interviewed them as soon as they agreed to participate. The interviews were transcribed immediately after the interview was completed. According to Malterud et al. a sample size of 17 women is sufficiently large to elucidate the aim of a qualitative study, when the aim is to cover the broadest possible range of variations of the phenomena studied. However, achieved saturation should always be considered.34 In our study saturation was considered as achieved after the 17 interviews as no further knowledge about the women’s experiences and needs emerged.

Conclusion and implications for practice

Our study shows that women diagnosed with osteoporosis without preceding osteoporotic fractures feel as if they are left in limbo. They need targeted and tailored information about osteoporosis. Furthermore they want information about DXA scan results and overall treatment options prior to the GP visit. They ask for support in self-management of the disease with increased focus on how to promote bone health. The study highlights the call for new approaches to women newly diagnosed with osteoporosis without preceding fractures. We suggest that the approach should be more focused on the advantages of being diagnosed with osteoporosis. The information given should prioritize ways to manage the diagnosis in daily life with less emphasis on having a chronic disease and the increased risk of fractures. Furthermore information of the result of DXA scans and different ways to manage the diagnosis in daily life should be given to the women prior to the GP visit. This would help women to be better prepared and thus be able to participate in the treatment decision-making process. Our findings may be useful for healthcare professionals when designing future healthcare services for optimal osteoporosis management. However, more research is needed to elucidate these issues.

Authors’ contributorship

The first and last authors were responsible for the design of the study. The first author conducted and transcribed the interviews and was responsible for organizing the analysis and drafting the manuscript. All authors contributed to the analysis and the draw up of the final manuscript.

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Declarations of conflicting interests

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Ethical approval

According to Danish law, studies of non-biomedical character should not apply for scientific permission. The Danish Data Protection Agency approved the study (J.no. 2006-58-0035). All the participants received verbal and written information before signing the informed consent. They were all informed about confidentiality and the right to withdraw their consent to participate. Personal details have been changed to secure that the participants are not identifiable.
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