


Help at hand: Women's experiences of using a mobile health application upon diagnosis of asymptomatic osteoporosis

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Abstract

Objectives: This study aims to test a mobile health application (mHealth app) developed to meet the needs of women newly diagnosed with asymptomatic osteoporosis. We investigate how the women experience using an mHealth app upon diagnosis of osteoporosis and whether the app can help them to be prepared for treatment decision-making and support them in osteoporosis self-management. We also tested the usability of the app, to find out whether any adjustments were necessary prior to implementation.

Methods: A test was conducted at a Danish university hospital with 18 women aged 50–65, newly diagnosed with asymptomatic osteoporosis. On presenting for a bone density scan at the hospital, they were provided with the app, which was named 'My Osteoporosis Journey'. Data were collected through semi-structured interviews. Giorgi's descriptive phenomenological method guided the data analysis in four steps.

Findings: In total, 17 women succeeded in downloading the app, thereby accessing information on asymptomatic osteoporosis, their bone density scan results and treatment recommendations prior to visiting their general practitioner. Three overall themes were identified. Women experienced that the app (1) gave a feeling of confidence and reassurance, (2) prepared the women on treatment decision-making in the general practitioner visit and (3) provided help at hand in self-management of osteoporosis.

Conclusion: Our findings show that the mHealth app helps women to feel confident and reassured upon diagnosis of asymptomatic osteoporosis. The women felt that the app promoted an equal dialogue in the osteoporosis consultation since they felt prepared for visiting their general practitioner and were able to articulate their individual needs regarding treatment. After diagnosis, the women felt that the app provided support in self-management, right at their fingertips.

Keywords

mHealth, applications, participatory design, osteoporosis, self-management, women's health

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Introduction

Previously published studies on women's experiences of receiving a diagnosis of osteoporosis without preceding fractures have shown that they feel 'left in limbo' and find it

difficult to be diagnosed with an invisible disease.^{1,2} Patients diagnosed with osteoporosis without fragility fractures seem to be more worried and more anxious about the increased risk

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of fractures than those who have suffered from osteoporotic fractures.^{2–4} Hansen et al.^{5,6} found that improved support for women to understand osteoporosis upon diagnosis is required, together with support in self-management of the disease.

Mobile Health applications (mHealth apps) have been found to have potential to improve health outcomes for those living with chronic diseases.^{7–10} Despite the fact that, in 2014, Slomian et al. addressed the potential of using mHealth apps to support patients in self-management of osteoporosis, mHealth apps have not yet been implemented in the field. According to Slomian et al.,^{11,12} the reason for this might be lack of awareness of osteoporosis in the healthcare system, where other chronic conditions are given a higher priority than osteoporosis.

We sought to develop an mHealth app for women newly diagnosed with asymptomatic osteoporosis using a participatory design approach. Participatory design approaches require a clear understanding of the clinical problem and entail the continuous involvement of users.^{13–15} Participatory design originates from action research and thus combines the use of qualitative research strategies for bringing about change through action and improving practice.^{16–18} New healthcare technologies developed through a participatory design approach have often shown to be successfully implemented.^{17–21}

This study reports findings from phase three in a participatory design study. In the first phase, we identified women's needs.¹ We found that women need targeted and tailored information about osteoporosis, with a focus on the advantages of detecting the disease prior to a fracture. They also need to be better prepared for the treatment decision-making process and they requested information on the dual-energy X-ray absorptiometry (DXA) scan result in advance of the osteoporosis consultation. After diagnosis, they need improved support in self-management of osteoporosis in their daily lives. In the second phase, we designed and developed an mHealth app in an iterative process together with a team of users, healthcare professionals and app designers at a Danish university hospital.²² A prototype of the app 'My Osteoporosis Journey' has been fully developed. In the third phase, the aim was to test the final prototype of the mHealth app in a clinical setting among women who did not participate in the design and development process. We wanted to explore how they experienced using the app upon diagnosis and to explore whether such an mHealth app could help enhance preparation for treatment decision-making and offer support in osteoporosis self-management. We also tested the usability of the app among the participants, to find out whether any adjustments were necessary prior to its implementation at the hospital.

Methods

Setting

In the Danish healthcare system, general practitioners (GPs) are responsible for referring patients at risk of osteoporotic fractures to a bone density scan – called a DXA scan in a

hospital. The hospital physicians write a description of the result of the scan before a report is sent to the GP, who is responsible for providing the patients with the result and the subsequent treatment recommendations. Between August 2017 and February 2018, women referred to a DXA scan at the Osteoporosis Clinic at Odense University Hospital were enrolled in the study if they fulfilled the inclusion criteria and agreed to participate. Inclusion criteria were access to a smartphone, tablet or a computer with Internet access, able to speak and understand Danish, aged 50–65 and a T score at -2.5 SD or below in the hip or lumbar spine. Exclusion criteria were non-Danish-speaking, previous osteoporotic fractures and severe mental disorders.

The following is a description of the content in the mHealth app 'My Osteoporosis Journey' and the process of using the app.

The mHealth app 'My Osteoporosis Journey'

A woman eligible for inclusion is offered the result of the scan by way of the app at the hospital. If she agrees to participate, she is given an information letter about the app and how to download it through the App Store or Google Play Store. The app is free of charge and available for both smartphones and tablets. The content is also accessible by way of a website. When the app is downloaded, the woman is provided with targeted information about asymptomatic osteoporosis and treatment recommendations. The laboratory specialist performing the scan enters the result in the web-based clinician interface. The result of the scan is automatically sent to the woman the next morning as a text message, together with a video and a graph illustrating the scan result. The patient can calculate her risk of fractures based on the result, as well as other indicators, using the algorithm of the Garvan Institute of Medical Research Fracture Risk Calculator.²³ Hospital physicians specialized within osteoporosis describes the result of the scan. Within 2 weeks, a report is sent to the woman's GP together with treatment recommendations. When the GP receives the report from the hospital, a message is automatically sent to the woman. In the meantime, she can prepare for the GP visit using an open-ended questionnaire embedded in the app. Examples of the open-ended questions are, 'Do you have any questions regarding your DXA scan result?' or 'Here you can write down your thoughts regarding treatment and discuss them with your GP'. If she has any questions while waiting for the DXA scan report to be sent to her GP, she can send a message to the Osteoporosis Clinic at the hospital through the app. In addition, she gets support in osteoporosis self-management through the app, with a focus on how to promote bone health. She is provided with a 12-week exercise programme including videos, a talk about a bone healthy diet and the chance to calculate her daily intake of calcium and vitamin D. She can activate reminders in the app to take medicine, do the exercises and calculate her intake of calcium and vitamin D and the time for the next scan (Figure 1).

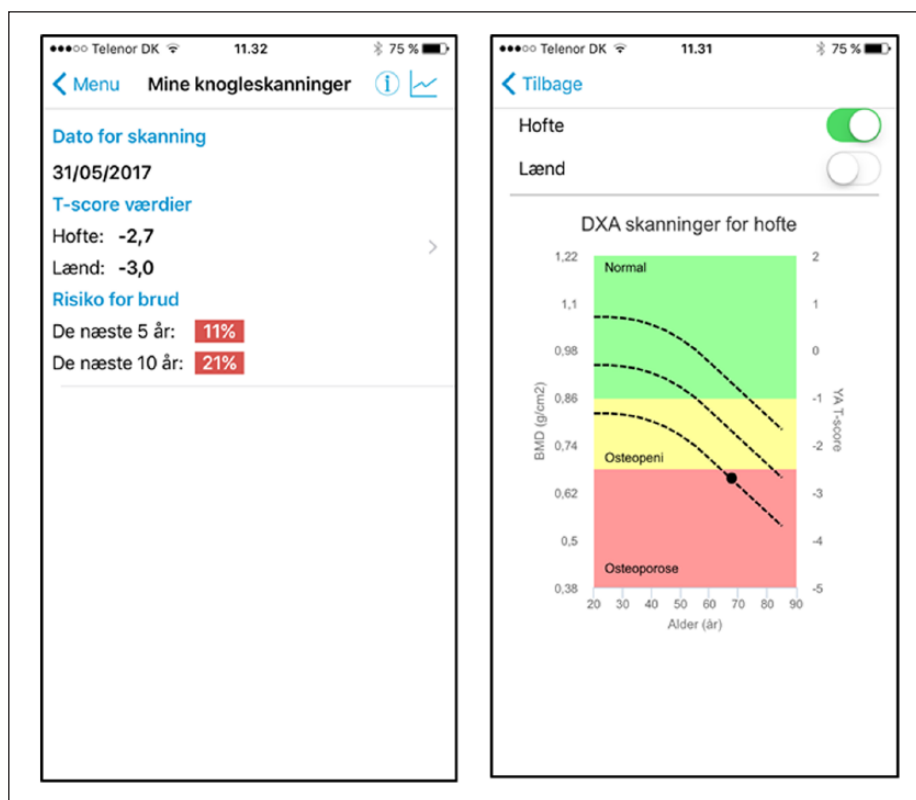


Figure 1. Screenshots from the app 'My Osteoporosis Journey'. On the left is the screenshot of the menu 'My bone scans', containing the result of the scan along with the T score and the calculation of fracture risk, the information icon and link to the graphs with the result of the scan, in the upper right-hand corner. On the right is the screenshot of the graph showing the result of the DXA scan in the hip.

The process by which women eligible for inclusion in the study get access to the result of the scan through the app and what happens in the app are illustrated in the flow chart (Figure 2).

Data collection

The laboratory specialists performing the DXA scan consecutively recruited women. All women eligible for inclusion were informed both verbally and in writing, prior to deciding whether they were interested in participating. Those who declined to participate were told there would be no adverse consequences for their care or treatment. Those who accepted participation agreed to receive the scan result through the app prior to the GP visit and participate in an interview. Informed consent was obtained by way of the app before the women received their scan result. In addition, informed consent was obtained prior to the interview, when the women had been informed about the aim of the interview and their rights. The first author (P.R.J.) contacted the participants by phone 14 days after the result of the DXA scan was sent from the hospital to their GP, to ensure that they had visited their GP and that treatment decisions had been made. If the women had visited their GP, they were invited to participate in the interview inside of few days. All the interviews were conducted within 4 weeks after the scan was

performed and the app was introduced to the women. Inspired by phenomenology, we developed an interview guide with open-ended questions and conducted semi-structured individual interviews with a focus on the women's experiences of using the app. P.R.J., who at that time was a female PhD student leading the research project and experienced in doing qualitative research, conducted all the interviews. The interviews were recorded and transcribed verbatim.

Data analysis

Giorgi's descriptive phenomenological method guided the data analysis, in four steps.²⁴ First, the transcribed interviews were read several times to achieve an overall impression of the data and a better sense of the whole situation being studied. Second, the texts were more carefully read through and meaning units were determined. Third, the meaning units were rephrased and overall themes were identified. Finally, the themes that emerged across the interviews were condensed to reveal the essence of how the women experienced the app.²⁴ The analysis revealed a general structure with three overall themes, which is presented in the Results section. The pattern of app use (e.g. which functionalities were used the most and when did they download the app) was also analysed. P.R.J. and J.C.

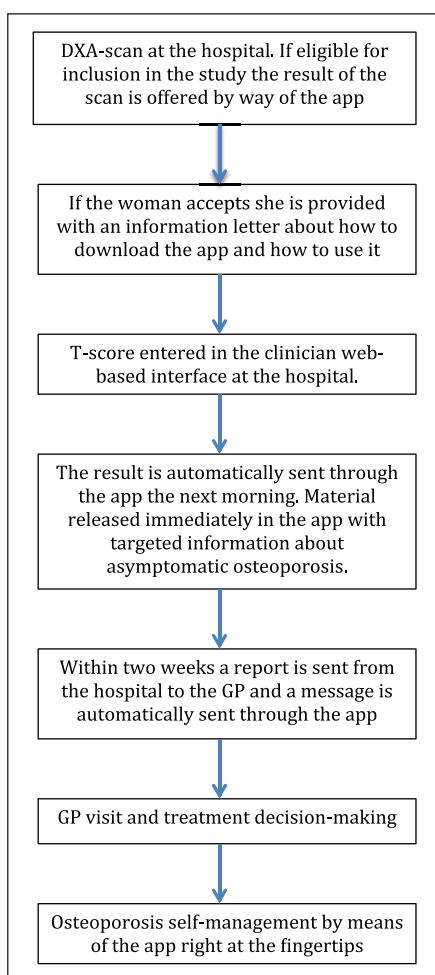


Figure 2. Flow chart about the process of using the app, from DXA scan at the hospital to the GP visit.

performed the first three steps of the data analysis. The overall identified themes were discussed in the research group of all authors (P.R.J., A.P.H., J.S., U.K.W. and J.C.) in the preparation of the manuscript and all the authors approved the final manuscript.

Findings

A total of 20 women were invited to participate in the testing of the app. Two declined due to lack of skills in using apps and technology in general. Thus, 18 women aged between 50 and 65 (mean age 57) were included in the study. Interviews lasted 15 to 61 min and were conducted based on the women's choice as a telephone interview (n=2), interviews in their own homes (n=12) or at the university hospital (n=4). Participant characteristics are shown in Table 1.

In all, 17 women succeeded in downloading the app or entering the web-based version before being interviewed. All but four women reported that technology was to some extent an integrated part of their daily lives. The four women who were not familiar with downloading apps reported difficulties

in downloading the app. Three of them succeeded with help from family members as this woman describes,

My daughter who is much more experienced in using apps and stuff like that helped me downloading the app and supported me in how to find the result of my scan. (WT 3)

The last woman reported that she had neither a smartphone nor a tablet and she planned to get help from her husband to use the web-based version. However, she did not succeed:

When she told me that I could have the result of my scan the next morning I decided to participate in the study. At home I asked my husband to help me enter the web-based version since we do not have a smartphone. However, we did not manage and we did not know whom to ask for support. Instead I just visited my GP after a couple of weeks to have the test result as usual. (WT 16)

One participant (WT 18) had an older smartphone (iPhone 4) and experienced that the app did not function. Since she was familiar with using technology, she used the web-based version instead. Table 2 illustrates the self-reported use of the different functions in the app at time of interview and demonstrates the pattern of app use.

As Table 2 shows, the pattern of the app use differs among the women. The three most frequently used functions were the written information about osteoporosis in women without preceding fractures, reading the message about the result of the DXA scan and the graphic representation of the DXA scan, in the menu called 'My bone scans'. The three least frequently used functions were sending a message to the Osteoporosis Clinic at the hospital, a questionnaire with open-ended questions to prepare for the GP visit and reminders. In general, the participants tended to focus on the functions that could help them to access the result of the scan and understand what it meant for them. The functions that could support the women in osteoporosis self-management in their daily life, called 'My material' and 'My bone account', were used by half of the women.

The data analysis identified three overall themes. Women experienced that the app (1) gave a feeling of confidence and reassurance, (2) prepared the women on treatment decision-making in the GP visit and (3) provided help at hand in self-management of osteoporosis.

The app gave a feeling of confidence and reassurance

Being provided with an app at the hospital right after being scanned gave a feeling of confidence in the women; they trusted the content of the app because it came from a hospital, as one participant stated in the interview:

It is nice to get something in your hand from the hospital, because then you know you can trust the content. (WT 9)

Table 1. Participant characteristics.

Participant code (WT ^a)	Participants' characteristics	Familiar with downloading apps	Way of using the app	Duration of interview
WT 1	Age 59, nurse, referred to DXA scan due to a known risk factor of osteoporosis, T score ^b : -2.6/-1.8	Yes	Tablet and smartphone	53 min
WT 2	Age 55, cleaning lady, referred to DXA scan due to known familial predisposition, T score ^b : -3.9/-2.5	Yes	Smartphone	38 min
WT 3	Age 59, medical secretary, referred to DXA scan due to a known risk factor of osteoporosis, T score ^b : -3.1/-2.2	No	Smartphone	47 min
WT 4	Age 57, employed by a bank, asked for a DXA scan due to known familial predisposition, T score ^b : -2.8/-1.2	Yes	Tablet and smartphone	41 min
WT 5	Age 55, social/health care worker, asked for a DXA scan due to known familial predisposition, T score ^b : -2.9/-2.2	Yes	Smartphone	45 min
WT 6	Age 57, child minder, referred to DXA scan due to known risk factor of osteoporosis, T score ^b : -2.5/-1.9	Yes	Smartphone	42 min
WT 7	Age 52, caretaker, asked for a DXA scan due to known familial predisposition, T score ^b : -2.8/-1.6	Yes	Smartphone	35 min
WT 8	Age 61, early retired nurse, referred to DXA scan due to known risk factor of osteoporosis, T score ^b : -2.7/-2.2	Yes	Smartphone	58 min
WT 9	Age 56, nurse, asked for a DXA scan due to known familial predisposition, T score ^b : -2.5/-1.6	Yes	Smartphone	36 min
WT 10	Age 58, nurse, asked for a DXA scan due to a known risk factor of osteoporosis, T score ^b : -3.1/-0.9	Yes	Smartphone	45 min
WT 11	Age 63, early retired accountant, referred to DXA scan due to at risk of osteoporosis, T score ^b : -3.3/-1.2	No	Tablet	17 min
WT 12	Age 50, office worker, referred to DXA scan due to a known risk factor of osteoporosis, T score ^b : -2.7/-1.2	Yes	Smartphone	34 min
WT 13	Age 65, retired cleaning lady, asked for a DXA scan due to suspicion of osteoporosis, T score ^b : -2.7/-2.0	Yes	Smartphone	38 min
WT 14	Age 56, office worker, asked for a DXA scan due to known familial predisposition, T score ^b : -2.9/-1.7	Yes	Smartphone	37 min
WT 15	Age 59, early retired, uneducated, referred to DXA scan due to known familial predisposition, T score ^b : -2.9/-2.1	No	Smartphone	56 min
WT 16	Age 55, kindergarten teacher, asked for a DXA scan due to known familial predisposition, T score ^b : -2.6/-2.2	No	(None)	15 min
WT 17	Age 55, lawyer, referred to DXA scan due to suspicion of osteoporosis, T score ^b : -2.8/-1.1	Yes	Tablet and smartphone	61 min
WT 18	Age 63, retired office worker, asked for a DXA scan due to known familial predisposition, T score ^b : -3.8/-1.5	Yes	Web-based	50 min

DXA: dual-energy X-ray absorptiometry.

^aWT: participant code. Refers to woman testing the app.

^bT score lumbar spine/hip.

The opportunity to have the result of the scan the next morning by way of the app was the main reason the women agreed to participate in the test of the app. Despite not being familiar with using apps, this woman still accepted to participate in the test of the app because of the opportunity to have a rapid answer of the scan:

Actually I do not know how to use apps and stuff like that. However, when she told me that I could have the result of the scan the next morning by way of an app, I thought that was very smart and agreed to participate. (WT 11)

This woman also experienced difficulties in downloading the app and asked for help from her family members and succeeded in having the result of the scan and in reading the

written information about osteoporosis prior to the interview.

In all, 15 women downloaded the app immediately after they got home from the hospital to immediately access information about osteoporosis and to have the result of the scan the next morning (Table 2):

I downloaded the app immediately when I got home. Because I needed to have as much information about osteoporosis as soon as possible. (WT 10)

Some women got help from their family members and read the message together with them, while others were alone. In total, 16 women succeeded in getting the result of the scan through the app prior to the interview (Table 2).

Table 2. Self-reported use of the app 'My Osteoporosis Journey' among the 18 participants at time of interview.

Functionality in the app 'My Osteoporosis Journey' and patterns of use	Self-reported use of the app (WT ^a code)																		
	WT 1	WT 2	WT 3	WT 4	WT 5	WT 6	WT 7	WT 8	WT 9	WT 10	WT 11	WT 12	WT 13	WT 14	WT 15	WT 16	WT 17	WT 18	
Difficulties in downloading the app on a smartphone or tablet		x									x								
Entered the app immediately after being scanned	x	x	x	x	x	x	x	x	x	x		x	x	x	x				x
Written information about osteoporosis in women	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
Videos with information about osteoporosis in women	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
Reading message with the result of the DXA scan	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
'My bone scans' (a graphic representation of the DXA scan results)	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
Video of the chief physician explaining the result of the scan	x																		
Sending a message to the Osteoporosis Clinic at the hospital																			
Risk calculator (calculating the 5- and 10-year risk of fractures)	x	x			x		x		x		x		x						x
'My material' – videos with exercise programmes	x				x		x		x		x		x						x
'My material' – a talk about bone healthy diet	x				x		x		x		x		x						x
'My bone account' – calculating daily intake of calcium + vitamin D					x		x		x		x		x						x
'My preparation' – open-ended questions to prepare for the GP visit					x														x
Reminders																			

DXA: dual-energy X-ray absorptiometry; GP: general practitioner.

^aWT number refers to the individual participant code. See Table 1 for characteristics.

They expressed that the message was easy to understand. Some women were at first surprised and read the message several times. Others had expected to be diagnosed with osteoporosis and therefore the message was not a surprise. In general, the women experienced that getting the result through an app downplayed the severity of the disease:

At the beginning, I was reading the result of the scan again and again and entered the app several times a day because it surprised me that osteoporosis was present in my bones. I think I had to understand it and what it meant to me. In this way, it is nice to have an app at your fingertips because you can easily go back when you need it. This helped me to understand that osteoporosis is not a serious disease. (WT 8)

The fact that the result of the scan was not so secretive somehow downplayed the severity of the diagnosis. (WT 17)

Together with the text message with the result, the women were also given a graphic illustration of the result, which they felt made it easier to interpret the result of the scan:

When I just look at the numbers (T-score) then I do not understand it. But then it is fantastic to have this (pointing at the functionality 'My Bone scans' in the app), because then I can have an illustration of my result on a graph. The graph was the main reason for my understanding of the result of the scan. Together with the text message, I think it is very nice. (WT 14)

For one participant, receiving a text message, a graphic illustration and the video of the chief physician helped her to easily understand her result of the DXA scan. This gave her a sense of confidence:

I can see that I have just passed the level for having osteoporosis and it is actually normal for my age. The chief physician mentioned this in the video when I got the result of my scan. So it could not be that bad. (WT 4)

A risk calculator is available in the app. It is based on the T score in the hip, age, number of falls within the last 12 months and number of fractures after the age of 50. The user has to enter the number of falls and number of fractures to get an estimated risk of fractures within 5 and 10 years. The result is given as a percentage. Five women used the calculator. Some of the women found it difficult to interpret the results, while others were reassured, if the risk of fractures was very low:

It is reassuring to see that the risk of fractures is that low. I'm just glad that the disease is detected, so that I can prevent the fractures. (WT 2)

Only three women sent a message to the Osteoporosis Clinic at the hospital. Those messages were questions about when the result of the scan had been sent to the GP because they were eager to visit their GP as soon as possible to initiate

treatment. Even though only three used this function, other women expressed that having the opportunity to send a message to the hospital through an app gave them a sense of reassurance:

I think it was nice to have the opportunity to send a message to the hospital if you were in doubt about something. It was like a lifeline to the experts at the hospital. (WT 1)

The app prepared the women on treatment decision-making in the GP visit

The app provides a questionnaire with open-ended questions to prepare for the GP visit. This was used by only two of the women (Table 2), and they felt that being prepared led to a feeling of entering an equal dialogue in the consultation:

I felt well prepared for the GP visit. I felt that the consultation was a more equal dialogue than I'm used to when visiting my GP. (WT 13)

Even though the other women did not use the questionnaire to prepare for the GP visit, some described the same feeling of having an equal dialogue with their GP:

I think that the meeting between us was very equal since we were both prepared and it seems like she also found it fruitful that I was so well prepared and did not have many questions. So, I think she was doing a good job this time and I left with the feeling of being well treated. (WT 14)

Most of the women felt that the app helped them to be prepared for the GP visit. The main reason for this was that the women had the result of the scan and information about the different treatment options prior to the GP visit. This helped them to come to terms with their needs regarding treatment:

When my GP suggested medical treatment, I was prepared, because I had read about it in the app. I could easily understand what she was saying and we agreed upon that I should start medical treatment. (WT 6)

Other women had concerns regarding medical treatment and by being prepared through the app they were able to articulate their concerns during the consultation:

I was very clear about the medication and that I did not want it. I think that the app helped me to be in a position to express that. (WT 8)

Being better prepared led to one woman feeling that she was given a better service in the consultation because the GP met her differently this time:

I think it is the first time my GP has been so well prepared. Usually, he just skims quickly over my test results. But, this time he engaged with me. (WT 15)

A message is automatically sent to the woman through the app at the point when the scan description is sent, along with treatment recommendations, to the GP. This is done to make sure that the woman does not contact the GP before the GP has received the official report from the hospital. However, four women contacted their GP before the GP had received the official description from the hospital, since they were not aware of the time lapse of up to 2 weeks between their and their GP's receipt of the result. This caused different reactions among the GPs:

I sent an e-mail to my GP after I have received the message with the result of the scan, but she did not want to see me before she had received the report from the hospital. (WT 2)

He got both irritated and surprised that I had got the rapid result of the scan and he did not. He refused to decide on treatment before he had the official description and the treatment recommendations from the hospital. So, I just went home and waited for the message in the app. I received it the next day and then I could visit my GP once again to start treatment. (WT 12)

At the GP consultation, some women related the experiences of the app and others showed it to their GP. The GPs paid attention to the app in different ways. Some found it interesting and some ignored it and behaved as if the app did not exist:

I told her that I had got this app at the hospital. She seemed at bit irritated and ignored it. (WT 1)

I showed my doctor the app and he was very interested and said that it was a very good idea. He had never seen anything like it and he was very positive about the result of the scan being sent to me so quickly. (WT 7)

The app provided help at hand in self-management of osteoporosis

The women used the app in different ways in their self-management of the disease. They expressed that they used it most in the days immediately after download, on receiving the scan result, prior to the GP visit and right after. After diagnosis, the app was used for self-management support:

It is very helpful to have an app so that you easily can get support in how to manage the disease yourself. Then it is somehow easier to handle being diagnosed. (WT 1)

The functions 'My bone account' and 'My material' with exercises and a talk about bone healthy diet were designed to offer support. The functions were used in a different way. Most of the participants browsed through the content to check what they wanted to use. The exercise programme consists of 12 exercise videos, each containing a 20-min workout, to be followed twice a week to strengthen the bones. However, only five women did the exercises twice a week:

I follow the exercise program on my computer twice a week. I have come to week number 4. It is quite hard, I think, but it is good too. (WT 18)

Others looked at the instructions for the exercises and implemented them in other activities, such as in the fitness centre or in other fitness training sessions.

The talk about bone healthy diet was played once the women were diagnosed and afterwards it was used as a brush-up if in doubt about anything regarding self-management:

I know where to find it if I'm in doubt about something. That's the good thing about having help at hand through an app. (WT 5)

Seven women used the 'bone account' extensively to calculate their daily intake of calcium and vitamin D, from immediately after being diagnosed:

Now I only use it if there is something I'm in doubt about. That could for instance be to check my daily intake of calcium and vitamin D and whether I need to take supplements. Then I just take the app out of my pocket and find the answer by using the calculator. And now that I have learned how to manage osteoporosis through the app, it is easy to let osteoporosis be a part of my daily life. But, I do not use the calculator that much anymore. Now I just do it (take the supplements if the daily intake of calcium and vitamin D has not been sufficient). (WT 10)

Two of the women who succeeded in downloading the app requested support to get started with it. They were of that opinion that the laboratory specialist could have better introduced the app at the hospital. They would have liked to be informed about whom to call if they were in doubt about some of the functionalities. One of the women had prior to her interview not used the app for osteoporosis self-management because she was in doubt about some of the functionalities:

I think it is smart (the app). But I think I would have used it to a greater extent if I have been better introduced to it at the hospital. (WT 9)

The diagnosis of asymptomatic osteoporosis meant that the participants' needs around understanding and managing the disease were different to those of fracture patients. They felt that they were not regarded as real patients and most of them did not want to be placed in the role of an ill person. However, they needed support and care upon diagnosis. One woman expressed that the app had given her the feeling that the healthcare system took care of her, even though she was not really sick:

I think that the app contributes to the feeling of being taken care of in the healthcare system among us who are not really sick. Though I'm not a real patient, I still need support to manage osteoporosis. By being provided with an app I feel that I get easily accessible support without feeling placed in the role of an ill person. (WT 17)

Discussion

Our findings are highly relevant to the ongoing debate in the healthcare system about whether or not patients should have direct access to their data and laboratory tests.²⁵ Not surprisingly, studies have shown that most patients prefer immediate access to their test results.^{25,26} Today, technology enables patients to get rapid test results and to receive diagnoses on their smartphones or on the Internet. At the Osteoporosis Clinic at Odense University Hospital a laboratory specialist performs the DXA scan. Even though the result of the scan (the T score) is available once the laboratory specialist has analysed the measured bone mineral density, the woman is informed that she has to contact her GP to get the result. The reason for this is that the physicians from the Osteoporosis Clinic have to evaluate the DXA scan results. They describe the result and supplement this with a treatment recommendation, if osteoporosis is present. A report is sent to the GP within approximately 14 days. The woman is informed about the DXA scan result at her next visit to her GP. The GP tells her that she has to undergo biochemical testing to make sure that no underlying disease is present. She is prescribed pharmacological and non-pharmacological treatment, in accordance with the clinical guidelines for postmenopausal asymptomatic osteoporosis.²⁷ In our study, we made the scan result available to patients through an app, as a supplement to the traditional osteoporosis pathway – in which the result is sent from the hospital only to the GP, and patients have to visit their GP to access it. Being able to have the result quickly through an app was the main reason for women saying yes to participation in its test. They felt confident about the app because they got it from a hospital and they believed that its content would be validated medical information based on evidence. Likewise, Derbyshire and Dancey have found that women are looking for mHealth apps that are trustworthy and evidence-based. Furthermore, the authors point out that all users should ideally be involved in the development and testing of mHealth apps.²⁸ Likewise we found participatory design to be a relevant research design in the development and testing of the mHealth app ‘My Osteoporosis Journey’.

The participants in this study felt that the information in the app helped them to be prepared to get the scan result the following morning; although some women nevertheless were surprised – mostly because they did not expect osteoporosis to be present in their bones. However, all of those who succeeded in receiving the message found the result easily understandable. They expressed that being able to reread the message in the app as often as they liked helped them to understand that it was not a serious condition. Reventlow, Hvas and Malterud have explored how pictures from a DXA scan affect women’s self-awareness. They found that women linked the scan result (a mark on a curve) to bodily fragility, which they incorporated into their bodily perception. They concluded that information about osteoporosis appeared to leave most affected women more uncertain

and restricted rather than empowered.²⁹ Likewise, a meta-synthesis showed that patients diagnosed with osteoporosis without preceding fractures seem to be the most worried and most anxious in relation to increased fracture risk, compared to patients who experienced a fragility fracture.² Therefore, in designing the app it was important to us to provide not only the DXA scan result as a message and a graph but also an explanation of what it could mean for the woman, with a focus on the advantages of detecting osteoporosis prior to a fracture. The women felt that the app and the easy access to their DXA scan result helped them to understand that asymptomatic osteoporosis is not a serious condition. None of the women participating in the third phase of this study felt that they had been ‘left in limbo’ as we had found in phase 1.¹ Instead, they felt that they were provided with help at hand by way of the app. In addition, the chief physician’s video was developed to support the understanding of the result. However, only seven women viewed this video. The reason for this was partly because it was not very clear from the menu in the app that there was such a video and partly because the women found the message and the graph easily understandable and they did not feel that they needed further information.

Even though the aim was to ensure that the women would not contact the GP before the latter had received it, some women contacted their GP the day after they received the result of the scan. The reason for this was a misunderstanding on behalf of these patients. They thought that the result of the scan would be sent to the GP and to them at the same time. However, we decided at the planning stage not to make any changes to the standard work process at the hospital that includes hospital physicians describing the result of the scan and giving treatment recommendations to the GP. Since it was a strongly expressed need among the women to have immediate access to the result, in order to prepare for the GP visit,¹ we decided to develop an app that would provide the women with the result on the morning after the scan.²² The plan was that the women could use the waiting time to prepare for the GP visit. Based on the findings, we will make it clearer in the app that a message will be sent to the patient from the hospital when the report is sent to the GP. This will help ensure that both the woman and the GP are prepared for the treatment decision-making session. The women who went to see their GPs at the appropriate time felt prepared and reported that the app contributed to an equal dialogue in the consultation. In this way, women concerned about negative side effects of medication could more easily put words to their concerns in the consultation. This is important in effective management of osteoporosis because fear of side effects is a factor that can deter treatment adherence.³⁰

Despite the fact that mHealth has the potential to facilitate adherence to chronic disease management,³¹ mHealth is not yet implemented in the field of osteoporosis. Our findings show that by providing support in the self-management of asymptomatic osteoporosis by way of an app, the women

experienced that they had help at hand and were engaged in a bone healthy lifestyle. There is, therefore, potential to implement mHealth in the field of osteoporosis.

Despite the positive results, our findings reveal that some adjustments should be made to the mHealth app prior to its implementation. Some women had difficulty in downloading and entering the app, and support was required by some to start using it. The main reason for this was lack of skills in using apps and smartphones. Thus, these women asked for support from family members. One woman (WT 16), who did not have a family member who was experienced in using apps or entering a web-based version of an app, did not succeed in receiving the result of the scan prior to the GP visit. Therefore, more emphasis should be paid to introducing the app more thoroughly at the hospital and make room for support if the patients experience difficulties in downloading and using the app.

Our study has some limitations. Only 18 women tested the app; hence, results cannot be generalized to all women newly diagnosed with osteoporosis without preceding fractures. One woman was unable to download and enter the app. Thus, only 17 women gave feedback on the app. Due to the small number of women participating in the test, it is difficult to predict how many newly diagnosed women would accept and use the app in a real-life setting. However, the intention of this study was not to generalize but, rather, to understand and investigate how women experience provision of an app when diagnosed with osteoporosis. With a view to our future development work, we are focussing on how we can improve support to patients in using their own smartphone to have access to their DXA scan results.

Malterud et al.³² argue that the prevailing concept for sample size in qualitative studies is saturation. A broad study aim requires a larger sample than a narrow aim to offer sufficient information power. We consider our aim to be broad and, hence, a sample size of 18 women is sufficient. Saturation was considered to be achieved, since no further information about the women's experiences of using an app emerged by the end of the analysis.

Conclusion and implications for practice

Our findings show that the mHealth app 'My Osteoporosis Journey' helps women to have a sense of confidence and reassurance when diagnosed with asymptomatic osteoporosis. Having an app and the result of the DXA scan at hand prior to the GP visit promotes an equal dialogue in the consultation and women feel able to articulate their individual needs regarding treatment. After diagnosis, the women feel that the app provides support in self-management right at their fingertips. Generally, our findings have shown that mHealth apps have some potential to support osteoporosis self-management. However, further work needs to be done to prove their use more widely.

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Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Ethical approval

According to Danish law, it is not necessary to apply for scientific permission to conduct qualitative studies, as they are of a non-bio-medical character.

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Informed consent

Written informed consent was obtained from all subjects before the study.

Trial registration

The study was approved by the Danish Data Protection Agency (J. no. 2008-58-0035).

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