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RESEARCH ARTICLE



Experiences of participating in a structured osteoporosis school in persons with established spinal osteoporosis – an interview study

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ABSTRACT

Introduction: Patient education in combination with physical activity has been proposed as a way of increasing health-related quality of life and functional capacity in patients with osteoporosis. A randomised pilot study called the School of Osteoporosis in Linköping (SOL) was conducted in 2018 for persons aged ≥ 60 years with established spinal osteoporosis. The SOL was scheduled for ten weeks with once-weekly theory education with or without additional supervised physical group training. The purpose of the present study was to explore the experiences of having participated in an osteoporosis school in persons with established spinal osteoporosis.

Materials and methods: Ten participants who had completed the SOL with patient education and supervised physical group training were invited to individual interviews, while six persons were accepted to participate. Qualitative content analysis was conducted with an inductive approach.

Findings: Three main categories were identified from the interviews: The structure of the osteoporosis school; Gained knowledge related to the education in the osteoporosis school; and Experiences of health status one-year post-intervention. Seven associated subcategories were identified. Increased knowledge and perceptions of improved health acquired by the interventions were emphasised. However, continued supervised group training was requested and there were also concerns about worsened health at the one-year post-intervention follow-up.

Conclusion: The tailored content and the group aspects of the structured osteoporosis school were experienced as the most important factors for successful results.

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Introduction

Osteoporosis is a systemic skeletal disease characterised by low bone mass and microarchitectural deterioration of bone tissue, leading to enhanced bone fragility and an increased risk of fracture [1]. The majority of individuals who have sustained a fragility fracture or those who are at high risk of fracture are still underdiagnosed and untreated [2]. Vertebral fractures are the most common osteoporotic fracture [3,4]. In persons who have experienced one vertebral fracture the relative risk to suffer another vertebral fracture is four times greater compared to those without a prior fracture [5]. A vertebral fracture may occur suddenly, for instance after lifting an object or bending forward. Such a vertebral fracture may give rise to acute and also chronic pain with fear, concerns and striving for independence in ordinary life [6,7]. It is reported that Swedish women with a clinical vertebral fracture have persisting decreased

physical health-related quality of life, for up to 18.9 years after the time of fracture [8]. Osteoporosis schools, i.e. patient education in groups, with interdisciplinary focus, are part of some health organisations. There is a considerable variation in these schools' content concerning theory sessions, timeframe, and the opportunity to supervise physical training (tailored exercises in groups) or not. Furthermore, the previous schools include different patient categories (osteopenia/osteoporosis/established osteoporosis) as well as fracture history [9,10]. Theory contents in the group education often focus on knowledge of osteoporosis, medication, fall risk prevention and nutrition. Furthermore, many osteoporosis schools include physical activity in various arrangements concerning the frequency and specific activity [9]. Thus, clinically relevant impact of osteoporosis schools on osteoporosis management is still unclear [10].

A pilot intervention study called the School of Osteoporosis in Linköping (SOL) was conducted in autumn 2018. The SOL-study

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was scheduled for ten weeks and included once-weekly theory education with or without additional physical activity. To be included in the SOL-study the participants had to fulfil four criteria; 1) being diagnosed with established spinal osteoporosis (i.e. osteoporosis and at least one vertebral fracture); 2) the most recent vertebral fracture should have occurred more than 3 months ago; 3) age 60 years or more; and 4) physical ability to move without an indoor walker. Patients with an inability to understand the Swedish language or difficulty following the research protocol or dementia were excluded. The participants for the SOL study were recruited by means of advertisements through the regional patient organisation, local newspapers and at the osteoporosis unit at Linköping University Hospital and eligible subjects were randomised into three groups; 1) theory only ($n=10$); 2) theory and physical training ($n=11$); and 3) theory and mindfulness/medical yoga ($n=10$) [11]. However, in the present study, we exclusively focussed on group 2, i.e. participants with theory and physical training.

The interventions included theoretical lessons organised as a 1-hour weekly theory session for 10 weeks, with a coffee break as a social event at each meeting. The theory themes of the SOL were; (1) Osteoporosis and physical activity; (2) Diagnosis of osteoporosis and pharmacological treatment, two sessions; (3) Mindfulness and medical yoga; (4) Orthopaedic technician aspects of activating spinal orthosis and stable shoes; (5) Nutritional aspects; (6) Balance performance and balance training; (7) Information from the regional patient association for osteoporosis; (8) Ergonomic aspects concerning daily living activities and adequate technical support; and (9) Physiology of pain. Physiotherapists, a physician, an occupational therapist, a nurse, an orthopaedic technician, a dietitian, and representatives of the national patient organisation contributed to these lessons. The physical training group was supervised by an experienced physiotherapist for 45 min once a week prior to the theory sessions. The exercise program was performed to music and started with a warm-up phase for 6 min, and then circuit training at nine training stations focussing on muscle strength and balance exercises for 45 s times 3 sets. The sessions were ended by 5 min cool-down and stretching. These participants also received a home training program.

As part of the evaluation and further development of a structured osteoporosis school, this qualitative interview study was performed to get a deeper understanding of the participants' subjective experiences after completion of the school. It is important to gain more knowledge on how the content of an osteoporosis school could be received by the participants and how such a school could be delivered to encounter the needs of older adults with spinal osteoporosis.

The purpose of the present qualitative study was to explore the experiences of having participated in the structured SOL with both theory education and supervised physical group training in persons with established spinal osteoporosis.

Materials and methods

Design

The design is a qualitative interview study, analysed by using qualitative content analysis with an inductive approach according to Graneheim & Lundman [12].

Participants and settings

One year after the completion of the SOL interventions those persons who had participated in the interventions with both education and physical training ($n=10$) were invited to participate in individual interviews. Six persons (five women and one man) were accepted to participate in the individual interviews. Median age was 74.5 years (range 65–82 years). The median time since the diagnosis of osteoporosis was 9 years (range 3–20 years). The most frequent vertebral compression site was the lumbar spine. In addition to the vertebral fracture, one person had a history of an upper arm fracture, three person forearm fractures, and two person fractures of the rib. Five informants were full-time retired and one person was part-time retired. There was a high attendance rate to the school sessions with on average 9 out of 10 (range 8–10) amongst these informants. At the end of the SOL, the participants reported that they were very satisfied with the content, using a 0-5 graded scale (0 = not content at all, and 5 = very content). They scored a median of 5 for the supervised physical training group and 4-5 for the theory lessons (7 out of 10 themes were scored a median of 5). From the questionnaires collected during the study, five out of 6 informants reported ≥ 150 physical activity minutes per week (national recommendation) [13] at baseline and post-intervention. At the 1-year follow-up one participant had suffered an accident making physical activity temporarily difficult. Thus 4 out of 6 informants reported an activity ≥ 150 min/week at the 1-year follow-up. Directly after the intervention period 4 out of 6 informants reported that they had made some active lifestyle changes due to attending the SOL. After one year the comparable figure was 3 out of 6.

The interviews took place at Linköping university hospital in January-February 2020.

Data collection

Two physiotherapy students (in the last semester before their graduation), who were new to the project, conducted the interviews. An interview guide with questions about the content of the theory education, experience of the supervised group training, group aspects, fall prevention and lifestyle behaviour, perceived pain and sleep quality was used as support for the individual interviews (Supplement 1). The interview guide was constructed according to the steps presented by Kallio et al. and had rather few open questions due to the characteristics of semi-structured interviews. The preliminary interview guide was first tested using field testing technique to make the questions more relevant [14]. The interviews lasted between 38 and 82 min with an average time of 61 min. All interviews contained rich descriptions of the informants' experiences. The interviews, which were performed in Swedish, were audio recorded and transcribed verbatim by the students.

Data analysis

At first, each interview was read several times by the students and their supervisor (AGK) to get a sense of the entire

interview. Thereafter, meaning units with similar content were extracted from the interview text, without changing the main content. The meaning units were classified, condensed, coded and grouped into main categories and sub-categories. The findings were discussed between the students and the supervisor, the researchers in the field of osteoporosis who had designed the SOL, and also with an associate professor from the physiotherapy program at Linköping university. The interview guide and the quotations were translated into English after the closing of the analysis.

Ethical considerations

The Swedish Ethical Review Authority, Linköping, approved the intervention study (Dnr 2017/543-31) and the qualitative interview study (Dnr 2019-06026). The SOL trial was registered at ClinicalTrials.gov, NCT05227976. All participants in the qualitative study received oral and written information on the purpose of the study and that the participation was voluntary and could be ended at any time. Informed signed consent was obtained from those who agreed to participate in the interviews.

Findings

Three main categories (A-C) and seven subcategories were constructed through the analysis: A) The structure of the osteoporosis school (three sub-categories; The importance of (social) group aspects, Adapted and inclusive design, and Requests for continued supervised group training); B) Gained knowledge related to the education in the osteoporosis school (two sub-categories; Increased knowledge about health factors, and Increased knowledge about risk factors); and C) Experiences of health status one-year post-intervention (two sub-categories; Physical and psychological changes, and Concerns about worsened health) (Table 1). The categories are presented using quotes (*in italics*) to support the analysis and to illustrate similarities and differences of the informants' experiences. The informants are designated P1-P6. Transcription conventions that are used are/ .../indicating omitted words, and [...] indicating authors' comments.

• A. The structure of the osteoporosis school

In this main category the informants' experiences of participating in the SOL is described, which encompasses both the importance of (social) group aspects, the adaptive and inclusive design, and also requests for continued supervised group training interventions.

The importance of (social) group aspects: Both the theory education and the physical training in the school were implemented as group activities, which were appreciated by the informants. They felt a friendly group atmosphere with a sense of belonging and also fruitful group discussions. They expressed that their motivation was increased by listening to other participants' obstacles and opportunities during the patient education, and also by exercising together in the physical training group.

"I think it was positive to meet other people and to listen to their discussions about the disease and how many thoughts there are about this [osteoporosis]."(P1)

"You get a greater understanding for not being alone with this misery" [osteoporosis]. Thus, it's obvious that it was useful/.../to meet others."(P2)

Adapted and inclusive design: The informants declared that the theory education content and information was well designed and adapted to their diagnosis. They had confidence in the lecturers who were experts in their specific topics and knowledgeable on how ordinary life would be influenced by osteoporosis and pain.

"I thought that it [the theory education] was very well adapted to our group. It was a good briefing, and it was just to pick the best pieces and try to remember how to live to achieve a good result."(P3)

The physical group training supervisor had chosen individually adapted exercises and suitable music, which the informants found encouraging and stimulating. The informants enjoyed and looked forward to the training sessions and felt that they had achieved something by exercising. The circuit exercises with varying degree of difficulty at the nine training stations were appreciated, as the exercises could be adapted to each participant's ability. Exercises which were performed in pairs were considered as especially nice and fun. The informants also benefitted from the individually adapted home exercise training program.

"I thought that it [the supervised group training] was good, as all [participants] managed it. Thus, you performed as you could."(P4)

Requests for continued supervised group training: The regularity and the structure of the group training sessions were stated as safe and were important components for the ongoing training period. However, the informants experienced that the SOL was abruptly ended and that the phasing out from the school was inadequate. They wished that the SOL group discussions would resume, and they asked for a corresponding group training to continue with in the community. The informants were uncertain whom they could contact and which training form would be adequate

Table 1. Main categories and sub-categories.

Categories	Sub-categories
A: The structure of the osteoporosis school	The importance of (social) group aspects Adapted and inclusive design Requests for continued supervised group training
B: Gained knowledge related to the education in the osteoporosis school	Increased knowledge about health factors Increased knowledge about risk factors
C: Experiences of health status one-year post-intervention	Physical and psychological changes Concerns about worsened health

according to their diagnosis and function. They were anxious about that any other form of physical training activities might be too loading and lead to injury.

"If I join another [training] group, such as a common gym group that I joined before, I don't know if I will overstrain the back."(P5)

"I can feel a little dissatisfied, as I have to [exercise]. I know as well, that this doesn't last. Now I have to find something new."(P4)

• B. Gained knowledge related to education in the osteoporosis school

This main category describes the informants' increased knowledge about health and risk factors concerning osteoporosis.

Increased knowledge about health factors: The informants reported that they had gained increased knowledge concerning living with the diagnosis of osteoporosis, how it can be treated and how to perform better self-care. They expressed that they knew more about the positive effects of physical activities and the importance of maintaining a good balance to avoid fall events. They also benefitted from the information on technical aids and expressed that an activating spinal orthosis as well as walking poles could facilitate everyday activities. Heavy lifts were perceived as bad and could cause damage. The informants expressed that they had gained knowledge about pain and how to cope with it after the SOL interventions. Their pain level was perceived as decreased and they had also a feeling of more wellbeing and happiness. The informants reported an increased self-efficacy as a result of the group training and patient education. There was still some uncertainty about how much pain that could be tolerated for different activities. Furthermore, an increased knowledge on coping with stress and that things must take their time were emphasised.

"Both the patient education and the training entailed that I regained this self-efficacy, and I thought it was good. I don't think that I will break any longer./.../I don't tense up in the same way."(P5)

Increased knowledge about risk factors: The informants had learnt to reduce their exposure to fall risk situations and to use strategies to reduce fall risks.

"You know what to watch out for [after the school], and that is to stumble on carpets and to fall on the whole, because that will be bad. Thus, we have taken some carpets away after all."(P2)

They also knew more about the negative effects of long-term sedentary and that it is important to take recurrent breaks from sitting by varying movement.

"We discussed not to sit too long, but to move more often between laps, even when you are sitting and watching TV or something like that./.../It's probably that sort of thing that slightly was an eye opener, it can be said, though you have heard it before."(P5)

The informants had learnt about the importance of nutritious food and the negative consequences of smoking and alcohol.

"I probably think that I find it more important, than I thought, to keep the body moving, to eat right and so - I think so. I suppose, that it is probably the school to give thanks for."(P6)

• C. Experiences of health status one-year post-intervention

This main category describes the informants' physical and psychological changes related to the school, but also concerns about their state of health at the time of the interviews.

Physical and psychological changes: The informants experienced that their balance performance had been positively influenced and that their ability to avoid and parry falls made them more relaxed and capable to treat ordinary situations.

"If I take a small misstep or if there is imbalance in the street, when I walk, I feel that I can cope. And it's rather nice."(P5)

A decreased balance ability was a limitation for some informants, who had a fear of stumbling and falling.

"Yes, it's the balance, it's very bad. I don't know why. It was probably why I fell/.../. When I go to town, I only visit one place./.../I can't run around as I did before."(P4)

Some informants who did not experience any persisting improvement said that they had not performed the home training program regularly.

"At first I believed that I felt better, but when I didn't continue with the [home training] exercises and the training and so on, then it has become worse."(P3)

However, the performance activity could indeed be perceived as enhanced compared to the period before the SOL interventions, as pain was no longer considered as such a limited factor.

Concerns about worsened health: There were informants who experienced a decreased performance capacity caused by their spinal osteoporosis, but also due to other comorbidities and accidents such as falls, reported at the one-year post-intervention follow-up. They expressed that their performance capacity was decreased because of stiffness and pain from different body locations, but also by fatigue. Increased pain could come and go for periods.

"It's irritating, as you know that it will not pass off. It's up to me if it'll be worse or if it'll be on the same level, yes, or change at all./.../I don't feel well always and I feel rigid. Then I feel stressed by it, huh. Then I think that I have to exercise. There are so many musts."(P3)

Perceived stress was also mentioned in conjunction with anxiety about worsening strength and decreased capacity in ordinary life, which exacerbated feelings of needing to catch as much as possible before the body would be too fragile.

"Thus, it's a form of stress that I have to catch up on as much as possible, before it becomes still worse. Until I have to drag myself forward with crutches or sit in a wheelchair or something."(P6)

Feelings of decreased function were a permanent reminder that something had to be done before the descending trend. Pain during activities could cause a worry for that something could have been broken in the body. Previous accidents with injuries were also a reason to increased fear and concerns about falls and fractures.

Discussion

Findings

The results from this qualitative interview study may be considered as a complement to a previous publication [11]. The three identified main categories: A) The structure of the osteoporosis school; B) Gained knowledge related to the education in the osteoporosis school; and C) Experiences of health status one-year post-intervention were differentiated from each other but had an interdependency.

The structure of the osteoporosis school with combined theory education and physical group training was appreciated by the participants. The positive (social) group aspects of the SOL and the individually tailored content were important factors for the informants. They got to know each other well and felt a high-ceilinged open-minded atmosphere during the education and group training sessions. In agreement with an observational and individual interview study on osteoporosis group education, the informants shared their experiences related to managing daily life with each other and with the teachers [15]. They had a common purpose of being group participants due to their experiences of having a fragile bodies. The experience of having similar problems such as vertebral fractures may foster such a sense of affinity in accordance with another qualitative study [16]. A trust-based dialogue between elderly fragile women with fall risk and their healthcare providers also seem to stimulate behavioural change in terms of maintaining an active lifestyle according to another qualitative study [17]. In the supervised physical group training activities with individually adapted circuit exercises the informants felt that they were in good hands. The regularity and the structure of the training sessions with individual guidance, encouragement and advice on adequate physical activities from the physiotherapist were very important components for the ongoing training period, which is in accordance with other quality studies on the experience of professionally supervised group training [18,19].

Gained knowledge related to the education in the osteoporosis school was experienced by the informants in specific increased knowledge about health factors, and also about risk factors related to osteoporosis, which resulted in physical and psychological changes. At the end of the intervention period, the informants expressed that they coped better with pain and had a greater sense of well-being, which is in accordance with a small study on osteoporosis school in primary health care [20]. In another interview study the participants expressed that they had reduced pain after group training interventions [16], which is in line with our findings. Furthermore, a randomised trial on women with established osteoporosis found that supervised group training had beneficial effect on pain intensity [21]. The informants also felt empowered to avoid exposure to fall risk situations and to use fall prevention strategies after the interventions, which is in agreement with another investigation [18].

Experiences of health status one-year post-intervention showed that stress and concerns about decline in health were existing among some informants. Such stress could

partly be age-related with feelings that time is precious and must be taken care of. Some informants had a bad conscience of not performing the home exercise training program. A sense of failure might have been experienced in those who did not maintain their healthy lifestyle habits. These persons might have remained in a pre-contemplation stage, and thus not have reached the patient's "stage-of-change" to permanent a behaviour change [22]. Continued supervised physical group training activities was requested after the intervention period. The informants felt uncertain about whom they would contact in the community to continue with appropriate training, as they were anxious that training leaders would not have enough knowledge and understanding to be able to coach them. Such a need for educational initiatives directed both to health care providers and to training/gym leaders in the community has been emphasised by other researchers, to enhance the knowledge of osteoporosis [17,19,23]. When designing and offering supervised physical training for osteoporotic patients in the community it is important to consider that lack of time and transportation are reported as common barriers to being able to join training groups, while flexible workout schedules and modified exercise plans are reported as facilitators [24].

Methodological considerations

The qualitative content analysis process was conducted in an inductive way, which means that conclusions are drawn from the informants' descriptions and not from predefined concepts or theories [25–27]. Trustworthiness is an overarching concept that encompasses several methods for describing aspects of trustworthiness such as credibility, transferability and authenticity in qualitative studies [27]. To achieve credibility the study was designed and data analysed through multi-professional disciplines input by coding and grouping meaning units into main categories and sub-categories. The present qualitative study was based on a small sample of informants ($n=6$), as not all participants who completed the SOL theory and physical training group did accept to participate in the interviews. Thus, the transferability is limited and might not be transferred to other settings, though our aspiration is that the given information could be used in other contexts. Authenticity was promoted by including quotes from the informants in the findings section, where both positive and negative experiences appeared [27]. The fact that the interviewers were neutral to the project and did not previously know the informants may be a strength of the findings. Reliability was increased by a team working between the students, the supervisor and the researchers in the field of osteoporosis, and also by an associate professor at Linköping university to reach a consensus when analysing the interviews.

Limitations

The sample was small and limited to a selected group of older Swedish persons with established spinal osteoporosis and thus might not be generalisable to younger persons

with the diagnosis osteoporosis. The findings might not either be transferable to men, as there was only one man amongst the informants. However, it has been described that changes in self can occur in men, as well as in women, after osteoporotic vertebral fractures with changes from being physically active to becoming less active [28,29].

Conclusions

The tailored content adapted for spinal osteoporosis and the group aspects of a structured osteoporosis school was experienced as the most important factors for successful results. Continued supervised group training was requested at the post-intervention follow-up.

Disclosure statement

The authors report that there are no competing interests to declare.

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