ORIGINAL RESEARCH



Understanding Patients' Perspectives and Educational Needs by Type of Osteoporosis in Men and Women and People with Glucocorticosteroid-Induced Osteoporosis: A Qualitative Study to Improve Disease Management

Catherine Beauvais ¹ · Didier Poivret ² · Eric Lespessailles ³ · Corinne Thevenot ⁴ · Dominique Aubraye ⁵ · Liana Euller Ziegler ⁶ · Martine Beranger ³ · Edith Filaire ^{7,8,9} · Sophie Gendarme ¹⁰ · Karine Legrand ¹⁰ · Yves Magar ¹¹ · Mickael Rousière ¹ · Florence Lévy-Weil ⁵ · Bernard Cortet ¹² · Anne Christine Rat ^{13,14} · SOLID'OS Working Group

Received: 4 May 2019 / Accepted: 22 August 2019 / Published online: 10 September 2019 © Springer Science+Business Media, LLC, part of Springer Nature 2019

Abstract

The aim of the study was to investigate similarities and differences in health beliefs, experiences and educational needs by type of osteoporosis (OP), particularly in people with glucocorticoid-induced OP (GIOP) and men. A qualitative study was conducted via focus groups involving post-menopausal women with or without osteoporotic fractures, osteoporotic men and people with GIOP. Fifty-three participants were included in eight groups. A wide range of health beliefs was found for all types of OP. Osteoporosis was considered a natural consequence of ageing except in men or conversely a serious disease associated with risk of new fractures and disability. GIOP patients had heterogeneous knowledge of OP and reported fewer prevention behaviours, and their quality of life was affected by the causal illness. Men had difficulties coping with the loss of their functional abilities and felt that OP was a "women's" disease. Beliefs about treatments ranged from confidence to fear of adverse effects or doubt about efficacy in all types of OP. Participants were interested in physical activity, fall prevention and diet, and preferred group sessions. GIOP patients and men had an interest in face-to-face education. Men were also interested in brief information including via the Internet. Patients' beliefs about OP differed by type of OP. Specific populations such as men or people with GIOP need particular care owing to experiences and needs. Offering group sessions in educational interventions is of interest to allow for sharing experiences and also face-to-face education for men and GIOP patients or the Internet for men.

Keywords Post-menopausal osteoporosis · Glucocorticoid-induced osteoporosis · Male · Qualitative research

Background

Osteoporosis (OP) and the resulting fractures are associated with increased morbidity, mortality and healthcare costs. The condition is widespread among post-menopausal women [1]. Men have a four times lower rate of OP than women aged 50 years and older [2], although the assessment of OP prevalence in men varies depending on the country

The members of the SOLID'OS Working Group are listed in the acknowledgments.

☐ Catherine Beauvais catherine.beauvais@aphp.fr

Extended author information available on the last page of the article

and age [1, 2]. OP in men has specific aetiologies such as hypogonadism, alcohol abuse and smoking [2, 3]. According to a recent review on sex disparities in OP [1], men are under-screened for OP and undertreated even when they have fractures, which suggests possible unmet needs among physicians and patients. In addition, regardless of age or comorbidities, men have a higher risk of mortality after hip fracture [2].

Glucocorticoid-induced OP (GIOP) is the most frequent cause of drug-induced and secondary OP [4]. The main reasons for glucocorticoids (GCs) use are inflammatory rheumatic diseases (rheumatoid arthritis and polymyalgia rheumatica) and lung diseases [4]. Data on the prevalence of GIOP are scarce. In the Global Longitudinal Study of Osteoporosis in Women (GLOW) that enrolled 60,393



post-menopausal women, 4.6% were receiving GCs at base-line visit and 73% declared they were GC non-users during a 3-year follow-up [4, 5]. In patients receiving GCs, the risk of fractures is increased by twofold and the risk of vertebral fractures is even higher [4]. The global prevalence of fractures has been reported to be 30% to 50% [4]. However, patients receiving GCs remain under-screened for GIOP: in the GLOW study, the number of individuals screened for bone mineral density (BMD) was low (\leq 51%) in current continuous GC users [5].

Guidelines for managing post-menopausal OP (PMO), men with OP and GIOP include pharmacological and nonpharmacological treatments [4, 6–10]. Management of OP involves several issues, including poor medication adherence [11, 12], lack of motivation for exercise and low calcium intake [13]. These barriers lead to low rates of optimal management despite the existing guidelines and the availability of effective treatments [14]. These issues are not well known in the particular populations of men and GIOP patients. A review of factors associated with poor adherence concluded that being a man favoured poorer adherence (11 studies in favour vs. 2 not in favour) [15]. Receiving GCs was not identified as affecting adherence, but receiving concomitant treatment for comorbidities was associated with lower adherence [15]. Patients with rheumatoid arthritis were more likely to have low adherence [15]; in a French cohort receiving bisphosphonates, having rheumatoid arthritis was associated with low adherence and persistence (odds ratio 0.37 [95% confidence interval 0.19–0.73] and 0.45 [0.25–0.81]) [12].

Similar to other chronic conditions, health beliefs affect decisions to initiate therapy or adhere to treatment and quality of life of people with OP [16–23]. Despite an increasing body of literature on patients' experience [24], we still lack insight into some populations such as patients with GIOP or men. To our knowledge, no study has investigated the perspectives of people with GIOP. For men, available studies are scarce. Only 3 qualitative studies addressed men's experience with OP, focusing on men's health with OP [25, 26] or including both men and women [27]. Results from a systematic review [24] showed that men were included in 10% of qualitative research. The men's perspectives have been mostly assessed by surveys of healthy men that used self-administered questionnaires [28, 29] or men at risk of OP (HIV infection) [30] and prostate cancer, undergoing active treatment or not [31]. The studies showed low OP knowledge [27–31] and low perceived susceptibility [29].

Although several educational interventions have been reported for OP, they had controversial results, particularly for medication adherence [32–36]. Some studies showed an improvement in medication adherence [34, 36] or non-pharmacological treatments [35], whereas others were ineffective [32, 33]. Only 3 of 5 of these studies included men. The

proportion of men enrolled was very low (6% to 11%), and no patients with GIOP were identified in the study populations. Awareness of patients' educational needs is essential to enhance self-management [37]. In a recent systematic review of the 16 qualitative studies [38], specific information needs were identified: the nature of the OP, the fracture risk, medication, self-management, the role BMD and follow-up. However, the proportion of men was only 13%, few information needs were directly expressed in the studies of men [25, 26], and no mention was available of whether patients received GCs. Concerning all OP types, the preferred format to address these needs has not been well established since the type of information support was addressed in only 5 of the 16 studies of the recent review [38].

In this context, the aim of the present qualitative study was to assess OP patients' needs by type of OP. We aimed to investigate (1) OP patients' health beliefs, experiences and knowledge of OP and its treatment by type of OP (i.e. PMO with fractures [PMO_f] or without fractures [PMO_wf], men with OP or people with GIOP); and (2) educational needs and expectations and the format preferred by the patients, particularly by men and GIOP patients.

Methods

Design

A qualitative approach was used for the study aim [39]. We chose a focus group methodology with group interactions to deepen the data collection. The study was initiated by a multidisciplinary group (SOLID'OS) including ten rheumatologists, three nurses, one occupational therapist, one dietician and two members of the patient association Association Française de Lutte anti-Rhumatismale (AFLAR). All SOLID'OS members had a special interest in OP research or management and/or patient education.

Interview Schedule

A standardized semi-structured interview schedule developed by the SOLID'OS group was used. The interview schedule was built in 2 steps: (1) the literature was reviewed and presented by a member of the group (MR) including recommendations for the management of OP, existing data on health beliefs of OP patients and existing literature on educational interventions, and (2) the interview schedule was developed according to the members' own experience. Four main domains were addressed: health beliefs about OP, life experiences and coping with OP, knowledge of OP, educational needs and expectations from health professionals. At the end of the focus group, patients were asked about their knowledge of patient educational interventions and which



format they would prefer to deliver information and education (Table 1).

Study Sample

Participants were recruited by members of the SOLIDOS Group on a voluntary basis from eight rheumatology clinics in semirural areas or in large cities in France. To obtain a sample with optimal diversity, participants were recruited from seven cities in France (Paris, Laon, Lille, Metz, Epinal, Orléans, Nice).

Eligibility criteria were the rheumatologist's diagnosis of OP regardless of the age of the patient, the current treatment or the patient's adherence to medication. Patients were excluded if they did not speak fluent French or had cognitive impairment.

To have homogenous group interviews and to detect differences by type of OP, participants were enrolled in 4 predetermined types of focus groups addressing the 4 types of OP: PMO_f, PMO_wf, men with OP and people with GIOP. Two focus groups were planned for each type of OP, 1 or 2 focus group interviews in each city. Patients with GIOP were enrolled if they had current GC treatment whatever the dose.

The interviews were performed by three researchers (YM, SG and EF) who were trained in conducting focus groups and research interviews but not OP. Each researcher was in charge of two focus groups. The interview guide was the same for the four types of OP to allow comparisons (Table 1). Participants could freely discuss issues of importance to them and their own experiences and representations. The interviewers were responsive to issues as they arose and asked for details when needed. They did not give their own opinion during the interviews so as to

prevent from influencing the participant's expression. Participants were informed of the study objectives and schedule of the study and gave their oral consent according to local recommendations.

Data Analysis

The interviews were audiotaped and transcribed verbatim. All data were de-identified to ensure confidentiality.

Transcripts from each focus group were analysed by using a thematic content analysis approach following a general inductive approach. All transcripts were read separately by the three researchers to obtain a global impression and to identify preliminary themes. A theme was defined as a topic sufficiently distinctive for the researcher to be recognized as providing important meaning regarding the research question. The interviews were further read and re-read to explore the meanings expressed by participants and to refine the preliminary themes and create a codebook. Transcripts were coded by using the codebook. Any themes that were not covered by the codebook were added and then merged into main categories. Illustrative quotes of each group were selected from these data. A face-to-face consensus meeting was used to harmonise the global results, choose meaningful quotes and develop implications for patient education and/ or OP management.

Results

The eight focus groups involved 53 participants (Table 2). Each focus group included 4 to 11 participants aged 44 to 90 years old. Sociodemographic characteristics are reported

Table 1 Interview schedule

Health beliefs about OP

Life experiences and coping with OP

Disease knowledge, beliefs and knowledge of pharmacological and nonpharmacological treatments.

Educational needs and expectations from health professionals

How patients view the organization of educational interventions

In general, what idea do you have of osteoporosis (OP)?

How did you react to the announcement of OP?

Are you feeling sick?

How do you live with OP?

Because of OP, are there any things that have changed in your life?

Is having OP a concern for you?

What do you know about OP?

In your opinion, what is the cause of OP? Do you know the causes?

What do you know about OP treatments?

Do you have any difficulties with taking medication?

Do you know of non-drug treatments?

What information, care or support do you need for your OP?

What would you like to know a little more about?

Do you have any idea about patient education?

Have you ever participated in patient education programs or have you ever heard of it?

What would patient education be of use in your case?

How would we motivate patients to come to patient education programs? What would we tell them?



Table 2 Sociodemographic characteristics of the focus group participants with OP

	PMO_f N=15	PMO_wf N=13	GIOP N=10	Men N=15
Sex (women)	15	13	9	0
Age group, years				
30–49				4
50–59	2	3	1	2
60–69	5	7	5	7
≥70	8	3	4	2
Occupation status				
Employed	3	4	1	6
Not employed	4	1		0
Retired	8	8	9	9
Level of formal education				
Primary school	2	4	1	2
≤High school	6	6	5	5
University	5	3	4	8
Residence				
Paris	0	0	5	6
Other regions than Paris	15	13	5	9
Area with ≥ 200,000 inhabitants	1	5	3	3
Area with 2000-200,000 inhabitants	5	5	2	10
Area with ≤2000 inhabitants	9	2	5	2
Occupation				
Farmer	1	1		0
Artisan, retailer	2	1		0
Executive, highly trained professional	0	5	2	6
Intermediate occupation	5	0	8	4
Office worker	4	5		3
Factory worker	1	0		2
No occupation	2	1		0

PMO_f post-menopausal OP with fractures, *PMO_wf* post-menopausal OP without fractures, *GIOP* gluco-corticoid-induced OP

in Table 2. In the GIOP group, all women but one was postmenopausal; half had a history of fracture; all had chronic and low dose GC treatment. Five had received high doses of GCs at an earlier phase of their disease. These 5 patients had vasculitis (n=2), giant cell arteritis (n=1), Crohn disease (n=1), and retinal vasculitis (n=1). The remaining patients presented chronic inflammatory rheumatic diseases, mostly rheumatoid arthritis.

The focus group sessions lasted 2 h, except for 2 focus group sessions, which lasted less (1h20 and 1h45) and one session that lasted longer (2h15), depending on the participant sample.

The thematic content analysis revealed 4 main themes: (1) health beliefs, disease representation and knowledge (Table 3); (2) impact of the disease (Table 4); (3) beliefs and knowledge of pharmacological and non-pharmacological treatments (Table 5); and (4) educational needs (Table 6). For each theme, the tables show the meaningful quotes as

well as the comments on the similarities and differences between men and GIOP patients on the one hand and PMO women on the other. Table 7 summarizes the highlights of these similarities and differences.

Health Beliefs, Disease Representation, Knowledge and Impact of OP

Health Beliefs, Disease Representation, Knowledge. Main Themes (Tables 3, 7)

OP as "Not a Real Disease" But a Natural Consequence of Ageing (All OP Types Except Men with OP) In all groups, except groups with men, several participants perceived OP as the normal consequence of ageing. Although causing fractures, OP did not seem a severe condition as compared with other chronic diseases such as diabetes. Fractures were considered common and self-limited events due to falls.



Table 3 Health beliefs, disease representation and knowledge by type of OP

Type of OP			
	PMO women. Quotes	Quotes on differences (D) and similarities (S) among men and GIOP patients versus PMO women	
OP is a natural consequence of ageing PMO_wf	"Women are more fragile" "It is a normal progression with aging"	Men 0 GIOP "It did not bother me because everyone at a certain age"	S D
OP is not a real disease. A trivial disease)	
PMO_f PMO_wf	"No, it was you, who spoke the word, but I never took that for a disease" "I find it hard to classifying it as a disease." "Osteoporosis is not really my problem"	Men 0 GIOP "I had a very early menopause, and cortisone for my rheumatoid arthritis, then a spontaneous fracture: it does not disturb me more than that" "Osteoporosis is an epiphenomenon that takes precedence" "It's not good news, but it's not vital."	N D
OP is a dangerous disease leading to the fear of falling			
PMO_f	"I am in charge of my Mom, but I figure that someday, my bones may break and then I may fall down." "Now I'm always afraid of walking and falling"	Men "The slightest accident from now, you can end in a wheeling chair." "You are always in the fear of breaking something"	S
PMO_wf	"It has gnawed my bones, I have no calcium left at all; The least fall, it is death." "If I ever fall and break my spine, I'm in a wheeling chair"	GIOP "It's a source of worry because I'm afraid of falling." "Besides, it's an insidious disease"	S
Knowledge about OP			
PMO_f PMO_wf	"It is a weakness of the bones, with risk of fractures." "There is a genetic background." "I know that at the time of menopause, you could have osteoporosis." "The spontaneous fracture, without falling, without anything. My mother had the same; it's more or less hereditary." "It's also a problem of diet"	 Men Men clearly identified the link between OP and the risk of fractures but some confessed they do not really know the risk factors "It's a bone problem, with fractures." "My bones, they will be hollow." GIOP The GIOP individuals expressed heterogenous knowledge on OP "It's a leak of calcium, so the bones are more friable." "It's the lack of sun the cortisone, it's a big factor." "I lack physical activity" 	S/D
Regretting the lack of prevention. Lack of information			
PMO_f	"As for mammograms, one could do bone density or blood test[s]. Men do blood test[s] for [the] prostate, so why not a test for women?"	The lack of information and prevention was a main subject among men and GIOP individuals Men "Why did they wait so long; it's a matter of money." "Screening people, they would be treated much earlier, and they won't get worse." "It would be necessary to inform people that OP also affects men, contrary to what one might believe."	Ω
		GIOP They did not understand why they were not screened for OP since they were followed up for the causal disease "Then, I had a touch of anger: why did not I get treatment that could have avoided it? I have always taken cortisone and with calcium, vitamin D and other medicines	Δ

lable 3 (continued)		
Type of OP	PMO women. Quotes	Quotes on differences (D) and similarities (S) among men and GIOP patients versus PMO women
Impact of OP diagnosis delivering. An additional disease	ase	
PMO_f	0	<i>Men</i> 0 D
PMO_wf	0	GIOP "Maybe for people who only have that but we who already have a disease" 'I reacted very badly" 'I spent two successive sleepless nights'.
Impact of OP diagnosis delivering		
PMO_f	0	Men A female disease for old people D
PMO_wf	0	"Once you are told that you have osteoporosis, you no longer live the same." "When you are told at 60 years old that you have osteoporosis, you are not delighted but it is less 'painful' than when you are 35 or 40 years old".
		Men "It is a disease for old people, for women; a disabling D disease."
0: Theme was not expressed		

OP as a Dangerous Disease (All Types) Some participants considered OP as a dangerous disease associated with the risk of new fractures and disability, leading to a fear of falls. Participants reported examples of serious OP with kyphosis in close relatives that made them consider OP as a severe condition.

Knowledge of OP (All Types) OP was identified as a bone fragility, with risk of reduced height and fractures. The level of knowledge appeared to be high in our sample. However, there was confusion, particularly in older participants and GIOP people, between osteoarthritis or the causal rheumatic disease and OP in terms of consequences and pain. Several women considered fractures as the consequence of falls only.

Regretting the Lack of Prevention and Information (All Types) In some individuals, the first fracture revealed OP, which made them regret the lack of prevention: OP could have been screened similar to other conditions, such as mammography for preventing breast cancer.

Health Beliefs, Disease Representation, Knowledge. Specific to Men and GIOP (Tables 3, 7)

Men The theme of OP not being a real disease or the consequence of ageing was not expressed by men. Knowledge was heterogenous, although men most clearly identified the link between OP and the risk of fracture. Some participants mentioned they had checked the Internet for confirmation of what the doctors had said.

A female disease for old people. Men specifically recalled the impact of diagnosis delivery because they were not aware that men could have OP. OP was perceived as a "feminine" disease. As a consequence, men particularly regretted the lack of information and prevention.

GIOP A trivial disease. Among several participants, OP was considered trivial as compared with the diseases that had needed glucocorticoid treatment. Expressed knowledge of OP was heterogeneous. An additional disease. Some individuals expressed anger or rebellion towards OP as an additional disease that they had to cope with and could have been prevented with appropriate measures.

Impact of OP. Main Themes (Tables 4, 7)

Reduced Daily Activities and Behaviour Changes (All Types) Individuals mentioned this main change in life style, as a consequence of the fear of falling and also as a natural way for preventing new fractures. This change led to inappropriate prevention behaviours such as limiting exercise and a permanent cautiousness in daily life. OP had an impact



Table 4 Impact of the disease by type of OP

PMO women	Quotes	Quotes and highlights on differences (D) and similarities (S)	
		among men and GIOP patients versus PMO women	I
Reduced activities			
PMO_f	"I can't carry my grandchildren. can't babysit my grandchildren and walk behind them"	Men Men are particularly affected by the incapacity of doing what S/D men usually do "I can't do certain activities anymore." "It prevents me from	S/D
PMO_wf	"I gave up many things. I hesitate before doing things"	GIOP This theme was shared with PMO women. However, the necessity of reducing activities is not well separated from the consequence of the causing illness "T have walking problems," "I stay only in my chair"	Q/D
Need to change behaviours		a Francisco Company of the Company o	
PMO_f	"I used to carry my laundry to the second floor, now I put it on the radiators." "If I get up at night, I switch the light on." "And now, I no longer put on my slippers.""I use my electric lamp, I am more cautious".	Men "I have to be cautious about things." "I am careful not to S break me anything"	70
PMO_wf	"I look careful where I set my feet." "I take care to remove all unnecessary carpets." "I have deeply changed my diet"	GIOP This theme was shared with PMO women. However, the need of changing activities is not well separated from the consequence of the causing illness "I do not go too fast; I pay attention if I have to climb on a stool." "Osteoporosis brought me to do exercise, I really should do a minimum of exercise."	S/D
Mood impact			
PMO_f	"Always having pain, it falls on the nerves." "You no [longer] feel like doing things." "For me, it has an impact on my mood, because I cannot walk"	Men Mood impact in men were related mainly to the loss of their S/D functional abilities. "Thave this disease constantly in mind." "You tend to suffer morally; you feel diminished"	S/D
PMO_wf	"It takes away my joy of living." "My mood took a serious hit; all is over"		S/D
Feeling of getting old or feeling older than their age			
PMO_f	"Maybe, one gets old faster"	Men "I look like an elderly person." "This is unacceptable to have S the life of an elderly person, when you're 46 years old"	7.0
PMO_wf	"I feel guilty, I feel I am getting old." "This refers to my grand-mother; I felt old when they told me." "I was not yet in the head of someone who had to pay attention to the carpets."	GIOP "I was not very happy, it reminded me of aging." "It affected my femininity"	ro
Fear of the future and dependency			
PMO_wf	"It annoys me to need other people"	Men "In my head, I have seen the wheelchair" S GIOP "It worries me because I have my mother who has osteopo- S rosis and I see other women completely broken."	70 70
Lack of communication			
PMO_f	"At home, nobody talks of it; I am the one who talks of it"	Men "I avoid talking about it; I'm bored when they say: take care S of your back"	7 0



lable 4 (continued)			
РМО women	Quotes	Quotes and highlights on differences (D) and similarities (S) among men and GIOP patients versus PMO women	
PMO_wf	"I don't talk [about] it with my colleagues, with my neighbours [either], it is not something to be done."	GIOP "We don't talk of OP with relatives." "There are advantages and disadvantages but not talking and acting as if everything was fine, is not good either"	S
PMO_f	"This is something invisible." "It should be said that it is a disease." "Osteoporosis is not taken seriously, except if there are repeated fractures."	Men "With the family, when you talk about your illness, at the beginning, it's OK but later on, they no longer understand." "When you go back to work, they don't take care any longer"	S
PMO_wf Ossitive coping. acceptance	"They see us moving, they do not realize"	GIOP "It stops relationships. This has changed my social life." "They do not realize in what state we are"	S
PMO_wf	"I believe that by accepting things, we live them better." "We have to move forward." "My children take care; my husband is with me"	Men and GIOP expressed more positive coping Men "I learned, thanks to the disease. I'm going towards the good." "That's the way it is." "I suffer, that's all." GIOP "We do not live with it all day." "I'd better accept, even though I control nothing."	д Д

on personal activities, shared activities with close ones and social behaviours, e.g. taking less care of their household or grandchildren.

Impact on Mood and Self-Esteem (All Types) The main reasons affecting mood were inability to perform valued or former activities, pain, feeling diminished and also fear of the future and dependency. Similarly, even though they had not experienced fractures, PMO_wf reported the same negative impact on mood and reduced activities.

OP also affected self-esteem and self-image: individuals felt being older than their age, although OP was often an invisible condition. Some women felt that it affected their femininity.

Lack of Communication (All Types) Most participants lacked family or social support. Most did not wish to share health problems so as to protect their relatives or because they did not want to appear as sick persons.

Feeling of Isolation and Lack of Understanding (All Types) Although they felt people understood them at first, participants explained that people tended to forget how they suffered and over time did not care about it any longer. The common opinion that OP is not a real disease was shared by relatives. The physical limitations also maintained the sense of isolation, because participants could not share daily activities with others.

Positive Coping, Acceptance (All Types) A few coping behaviours mentioned were acceptance, family support, downplaying and positive attitudes.

Impact of OP. Specific to Men and GIOP (Tables 4, 7)

Men Men had negative perceptions and self-esteem, and some had difficulties coping with the loss of their functional abilities. Some participants mentioned a dramatic disease representation, for example, the image of being in a wheel-chair. Men felt diminished by the incapacity to perform what was expected in terms of masculinity, affecting their role and appearance. Coping strategies were more expressed by men. Men were not likely to share with their relatives about OP to avoid being given advice all the time about what they should or should not do.

GIOP The impact on quality of life included the causal illness. The main difference with the other types was that participants reported fewer prevention behaviours. Along with men, the participants reported more coping strategies.



Table 5 Beliefs and knowledge of pharmacological and non-pharmacological treatments by type of OP

Type of OP	1		
	PMO women. Quotes	Quotes and highlights on differences (D) and similarities (S) among men and GIOP patients versus PMO women	
Knowledge of the principle and the objectives of treatment			
PMO_f	"One takes it to prevent having other fractures, prevent more osteoporosis."	Men "We will not rebuild the bones; we will stabilize things" S/I Men are attached to being able to "see" efficacy. They are talking about loss of efficiency "It didn't work for me, I didn't keep dropping, but I didn't increase"	S/D
PMO_wf	"We can't rebuild bones; it is lost, but we can slow down the evolution"	GIOP GIOP individuals has less spontaneous expression of knowledge "The treatment prevents worsening because we still have the treatment for rheumatoid arthritis"	Ω
Beliefs of efficacy. Trust in efficacy			
PMO_f	"It works well." "The treatment strengthens the bones"	Men "T m not cured but there is a tendency to see the curve S to improve"	S
PMO_wf	"I am confident, otherwise we would never do anything"	GIOP "If we are asked to take it, we take it." "If we did not S have treatment, we would get more fractures." "I am confident in my doctor"	S
Doubts about efficacy. Looking for proof of efficacy			
PMO_f	"I had a hormonal substitutive treatment for 7 years, but I think it's not effective, I still broke something"	Men "It never heals: my bone density is better, but is it due to S/I the drug?"	S/D
PMO_wf	"After a while, I think it doesn't have its effect any longer the body must get used to it" "To be frank, I no longer trust medicine"	GIOP "It is the bone mineral density that says if the treatment is effective: I lost 4 cm, so I still do not fix calcium; If I did, they would not give me all these medicines"	
	"Me, you know, I've already tried everything." "The doctors, they are kind of disarmed"	"One never knows if the treatments are effective." "There is s/l no evolution in one direction or the other." "One doesn't have enough perspective." "You wonder what this is all for"	S/D
	"He told me: we have pro and con data, so taking this uncertainty, it is better not to take anything"		
Concerns, fears			
PMO_wf	"I am anxious when reading the leaflet."	Men "I do not think I would take the risk of making an 'Aclasta' infusion" S GIOP "The treatment, it was badly brought, I was first told about the disadvantages before telling me about the benefits." "It scared me. I hesitated to take it even knowing at the same time that osteoporosis was very annoying." "It would have deserved further explanation"	ω ω



Table 5 (continued)			
Type of OP	PMO women. Quotes	Quotes and highlights on differences (D) and similarities (S) among men and GIOP patients versus PMO women	
Inconvenience and side effects PMO_f	"The side effects are quite annoying: stomach aches, constipation, muscle aches." "It is binding to remain standing for one hour, I have to get up earlier."	Men "One infusion once a year. I find it very good." "[Although] it was an injection every day, like a pen, it was much more acceptable than the treatment I had before." "The most boring is to take the tablets every week; you must learn to accept it. It's tiresome"	S/D
PMO_wf	"I can, as well take it in the morning as in the afternoon, or before going to bed: it bores me so much." "You have to wait half an hour, don't talk to me about it!"	GIOP "I'm allergic to drugs." "As to my treatments, I'm not racking my brain, it doesn't bother [me]"	S
Adherence PMO_f	"I often forgot and it's tiresome at the end." "Because it is binding, there are times when you want to stop"	Men The most annoying thing is to take the treatment, the tablets to take by the week, you have to know how to accept it. It's tedious Men Men noted the role if the spouse to motivate them "I had my wife who was incessantly behind [me], because the drugs, I am fed up of them, so there comes the moment when you don't take them anymore".	S D
PMO_wf Non-bharmacological treatment. Exercise. life style	"Last year I did not take it; I had other things to think of than myself."	GIOP "When it was once a week, I had to make a reminder." "If I forgot, it was a problem because it had to be taken on I an empty stomach." "If we are asked to take it, we take it."	S D
PMO_f	"Go [in] the sun, walk, continue to tinker about, have a quite normal life, [drink] enough milk." "The spa treatment, it is beneficial for the bones [we] must relax."	Men « you have to rebuild your muscles when you have this disease.»	S
PMO_wf Diet, alternative medicines	"It is necessary to deal with all this by good food, healthy lifestyle, exercises to avoid the falls." "Lots of exercise, walking, swimming"	GIOP "I do fitness with someone." "I walk slowly every day." S "Hiking." "Dancing though	S
PMO_f PMO_wf	"We have misconceptions about calcium" "Milk is not good for the adults"	Men only few men discussed diet "Dairy, cheese" GIOP Widely mentioned non-pharmacological treatment "A nutritionist told me not to eat gluten." "I was told to drink sheen's milk." "Homeonathy can help me to overcome this."	D D
T. C.		successions. Trouvelently can not have a covered and	

 $\underline{\underline{\mathscr{D}}}$ Springer

0: Theme was not expressed

Table 6 Educational needs by type of OP

idule o Educational needs by type of Or			
PMO women	Quotes	Quotes and highlights on differences (D) and similarities (S) among men and GIOP patients versus PMO women.	
Lack of information about PE. Needs for prevention			
PMO_f	"It should be said that it's a disease."I think it's good to talk about it, to encourage people to be screened and then start treatment right away so that they don't end up with fractures." "Take general precautions"	Men and GIOP shared the lack of information on PE	S
PMO_wf	"One must insist on prevention."	Men expressed that information was the job of the doctors. Few expressed educational needs "It's up to the doctor to do the job, but not to the patient education" "The real problem is there, what you're doing is very good but it's a little late for those who have the disease "If it's hereditary, inform how to prevent with regard to children, what to do"	Q
Educational needs. Content: non-pharmacological, diet	ช	GIOP PE could be of interest, but few expressed education needs "No, I've never heard of patient education". "Not at the time of the consultation because the doctor is not necessarily a pedagogue". "Educate the patient to take his treatment better."	Ω
PMO_f	"What time of the day to have meals for a better benefit". "I would like to have the list of foods most likely to strengthen the bones"	In men, this was not a prominent interest Men "What about milk? We still don't know what to do"	Q
PMO_wf	"We go home with the inability to take dairy products when they are recommended" "the importance of calcium must be emphasized. "I can't follow the advice they give me. »	GIOP Although expressing few spontaneous educational needs, GIOP individuals were interested by diet "It could bring us an improvement in diet» "a nutritionist told me not to eat gluten" "I was told not to take cow's milk because of enzymes that are difficult to assimilate" "I was told to have some sheep's milk"	∞
Content: non-pharmacological exercise, falls prevention	on		
PMO_f	"Gestures to do and not to do, how to stand. How to avoid falls »	Men Men were much interested in exercise "I would like to have information on the activities I can do, as to the powerplate". "Healthy life style, all the precautions to be taken, sport"	S
PMO_wf	"Not specifically on diet, but on follow-up, exercise, balance." "Even once a year, there would be a review where we do the exercises again, I'm sure I would discipline myself more. We would need a room a little larger than we can all do together, about ten people." "It's very good, there are movements that you can do the right way, you muscle your back well, I keep doing them at home."	GIOP GIOP individuals had no special needs on exercise or fall prevention	Ω



Table 6 (continued)			
PMO women	Quotes	Quotes and highlights on differences (D) and similarities (S) among men and GIOP patients versus PMO women.	
Content: disease and pharmacological PMO_f	"What is the bone and why it deteriorates from a certain time. And the drug, what exactly is its action. It is said to "fortify the bones", but to strengthen in what way?" "Are we going to have an evolution?" Why is it more women? When you explain a program it can halv you to take it more willingly."	Men and GIOP were more interested in knowing a lot on OP, on new treatments Men "We want as much information as possible "if we had all the elements that would allow us to choose what we want to do or what use an still do."	О
PMO_wf	"The treatment, to be told what to do and not to do	hey is the preventive? ventive treatment" e treatments, side effects,	Q
Content: sharing experience, empowerment, seeking help PMO_f this this this this this transfer to the transfer	'I think it's good to talk about it, we talk about lots of things" «"To incite people to be tested and immediately start treatment so as to prevent fractures ". "You're more confident about yourself"	42	Ω
PMO_wf	It is a disease that must be made known, by ourselves "We need to be helped to better live with the disease"	GIOP "we need to talk to each other to make us want to do things" "We need to exteriorise" "it would get me out"	S
Education format: groups, interactive			
PMO_f	"A small group is good, because everyone can give one's version. "There is a lot of exchanges, there are things you don't think about alone," One bounces on the ideas of one another ".)." It is better in collective, maybe it is more playful"	Men "Better in groups, small groups (5 or 6 people)"	S
PMO_wf	"Make everyone talk" "We don't want things to be explained, so that we have nothing more to say!" "It must be playful, not a magisterial course" "Gymnastics alone is dangerous, we risk doing more harm than good". "Walking alone it's true that in a group it's more friendly"	GIOP "for me, in group session, for in an individual session I already do it with my doctor" "A group of 10 once a month is fine" GIOP individual addressed being mixed with other kinds of OP "I think PE should not be the same for patients who have several diseases or for patients with only OP"	D S
Format: individual			
PMO_f	0	Some Men and GIOP had a preference for face-to-face education I Men "As if I wanted to give lessons to this gentleman, he won't listen to me, which is perfectly normal. Each case is individual. This gentleman who is very suffering, does not have the same reactions as the one who, like me, is lucky not to suffer."	Q
PMO_wf	0	GIOP "For me, in individual session: I don't want to hear the questions people ask and I don't want to expose my problems"; In a group, I would really feel down	



$\overline{}$
$\overline{}$
\sim
a)
=
_
_
_
_
=
_
$\overline{}$
$\overline{}$
()
٠,
$\overline{}$
_
o
_
a
_
=
0
_
_

PMO women	Quotes	Quotes and highlights on differences (D) and similarities (S) among men and GIOP patients versus PMO women.	
Other format PMO_f PMO_wf	0	Men «leaflets should be put in the doctors' waiting room; "Leaflets that one can have a look to from time to time" "There are reliable websites to which one can refer, where one can have a follow-up of the evolution of treatments" "Why not put photographs of the patients, so we would see that we are not alone"	Q
Format: trained health professional and others PMO_f	"Rheumatologist, dietician, physiotherapist, nurse; The gynecologist would have a role in motivating women "Even the GP could participate "The occupational therapist works on home adaptations and falls prevention. I would like to know how the psychologist can help us to have less pain?	Men Men have specific wishes "Only once would be enough, "a booster shot to see the evolution but that's all"	О
PMO_wf metion to retient education lack of metivation distance	need to have a holistic approach of the person, physically and entally" "at first, to get a document in case	GIOP "Trainers, they must not know less than we do, we need highly qualified and well trained people" "we need people who understand us" "psychologist"	S
PMO_f	"No need to go to the sessions." "I'd be interested, but I don't have time." "not to have a too long distance; to touch a rural population."	Men "it would be nice to have workshops on a town"	S
PMO_wf	3	GIOP "My internist told me it was rubbish" "not in hospital, since I've been ill, I've been going from my chair to the hospital."	S
PMO_f	"OP is not taken seriously by those around you" "I think he would Men and GIOP people are less keen into including close one in patient education sessions Men "Not involve then, I and my family, we do discuss it" "These are sessions between ourselves"	Men and GIOP people are less keen into including close one in patient education sessions Men "Not involve them, I and my family, we do discuss it" "These are sessions between ourselves"	Q
PMO_wf	"No, I made my husband participate, I made him read all the stuff I had had"	GIOP "I don't want to share with the man I love, I can talk to him but I don't want to be the sick person in our couple" "My husband, it's no need, he has progressed alongside with me" "My husband, it would be good for him to listen, because he does not realize our condition	Ω



Table 7 Summary of highlights of similarities (S) and differences (D) among men with OP and GIOP patients versus PMO OP women

Themes/sub-themes	Men (comments)	S	D	GIOP (comments)	S	D
Health beliefs, disease representation an	d knowledge by type of OP (Table 3)					
OP is a natural consequence of ageing	Not expressed by men		X	Shared with PMO women	X	
OP is not a real disease	Not expressed by men		X	Particularly shared with PMO women. OP is a trivial disease compared with the causal disease	X	
OP is a dangerous disease leading to the fear of falling		X			X	
Knowledge about OP	Clear identified link between OP and the risk of fractures		X	Heterogenous on OP and risk factors	X	X
Regretting the lack of prevention. Lack of information	Main theme		X	Main theme		X
An additional disease				Specific to GIOP		X
A female disease for old people	Specific to men		X			
Impact (Table 4)						
Reduced activities	Mood affected by reduced activities	X	X	Not separated from the consequences of the causal illness	X	X
Need to change behaviours		X		Not separated from the consequences of the causal illness	X	X
Mood impact	Due to the loss of functional abilities	X	X	Mixed with the causal illness	X	X
Feeling of getting old or feeling older than their age		X			X	
Fear of the future and dependency		X			X	
Lack of communication		X			X	
A feeling of isolation, lack of understanding		X			X	
Positive coping, acceptance	More positive coping		X	More positive coping		X
Beliefs and knowledge of pharmacological and non-pharmacological treatments (Table 5)						
Knowledge of the principle and the objectives of treatment		X	X	Heterogeneous knowledge		X
Beliefs of efficacy. Trust in efficacy.		X			X	
Doubts about efficacy. Looking for proof of efficacy.		X	X		X	X
Concerns, fears		X			X	
Inconvenience and side effects		X			X	
Adherence	Lack of adherence less spontaneously expressed	X	X	Lack of adherence less spontaneously expressed	X	X
Exercise, life style		X			X	
Diet, alternative medicines	Few discussed diet		X		X	
Educational needs (Table 6)						
Lack of information about PE.		X			X	
Information by physician			X			X
Prevention need		X			X	
Expressed educational need	Few expression		X	Few expression		X
Content: non-pharmacological, diet	Few expression		X		X	
Content: non-pharmacological exercise, falls prevention		X		Not expressed		X
Content: disease and pharmacological	Interest in knowing a lot, new treatments		X	Interest in knowing a lot, new treatments		X
Content: sharing experience, empowerment, seeking help		X	X		X	
Education format: groups, interactive		X			X	



Themes/sub-themes	Men (comments)	S	D	GIOP (comments)	S	D
Format: individual	Specific to men and GIOP		X	Specific to men and GIOP		
Other format (internet, brochures)	Specific to men		X		X	
Format: trained health professional and others	Short patient education		X		X	
Barriers to patient education: lack of motivation, distance		X			X	
Inclusion of close ones	Less than PMO women		X	Less than PMO women		X

Beliefs and Knowledge Regarding Pharmacological and Non-pharmacological Treatments (Tables 5, 7)

Pharmacological Treatments. Main Themes (Tables 5, 7)

Treatment Knowledge. Main Themes (All Types) The objectives and the principles of treatment were known: to prevent fractures, "strengthen" bone; diet, vitamin D supplementation, exercise, and the names of some specific treatments such as bis-phosphonates. However, calcium and vitamin D supplementation was cited before specific treatments, and the difference was not so obvious for all individuals.

Beliefs of Efficacy, Looking for Proof of Efficacy (All Types) The discourse about efficacy was heterogenous: some individuals expressed confidence with their treatment and medicine and others had prominent doubts. In one focus group of PMO_f women, individuals most trusted their treatment and their rheumatologist and reported few adverse effects. In the other focus group, most women did not believe the treatment was efficient. Doubts about the treatment's efficacy were predominant among PMO_wf women. Frustration was induced by the beliefs that OP could only be stabilized but not cured, that "the body can get used to" specific chemical treatments versus natural treatments such as calcium and by the lack of evidence of efficacy.

Fears, Inconvenience, Adherence (All Types) Surprisingly, only a few participants spontaneously mentioned fears about medication, when "reading the leaflet". Individuals were more inclined to talk about the medication constraints than side effects. Although they did not openly declare poor compliance, most participants mentioned they had forgotten or stopped their treatment.

Non-pharmacological Treatments. Main Themes (Tables 5, 7)

In all groups, individuals had knowledge of non-pharmacological treatments that provided a general feeling of empowerment versus specific medications more likely to be imposed upon them. However, they mentioned concerns about diet, especially milk. All groups reported inconsistencies in the advice given by healthcare professionals, e.g. regarding diet.

Pharmacological and Non-pharmacological Treatments. Specific to Men and GIOP (Tables 5, 7)

Men Men had rather good knowledge of medication and shared with other OP types the issues on medication (i.e., efficacy, side effects and adherence). Some mentioned the role of their spouse to motivate them to take drugs. Men seldom addressed diet. They generally agreed with exercise, although sometimes exercise or physical activity was difficult to perform.

GIOP People with GIOP had heterogenous knowledge of pharmacological treatment. They had difficulty identifying their OP medication among all their other medications. They needed objective proof and relied on BMD results to determine the efficacy of the treatment. They did not declare poor compliance, but most of their quotes tended to prove difficulties with medication, and more doubts about efficacy than others; several participants explained, "they were fed up" with drugs.

Educational Needs (Tables 6, 7) Main Themes

Main Themes

Lack of Knowledge of Patient Education. Need for Prevention. Barriers (All Types) Only a few participants had heard about self-management interventions or patient education (PE). After having PE explained, many regretted that PE was not provided before the fractures (PMO_f). Participants also wanted the general population to know that OP is a real disease. Barriers to attending PE sessions would be lack of time or motivation.



Educational Content

Non-pharmacological Treatments as First Line (All Types) PE content should focus on non-pharmacological treatments. PE could help clarify the contradictory information about diet, although participants were not sure they could follow the advice. PMO_f women focused on fall prevention. Non-pharmacological treatments were considered a holistic change in lifestyle.

Information About the Disease and Pharmacological Treatments in Second (All Types) Need for information on medication was second to non-pharmacological treatment.

Format of patient education (all types). PE should be a moment to share experiences, seek help from other patients and health professionals and find ways for empowerment. Patients could have a role in warning other patients (PMO f women) about the consequences of inadequate management. Participants had a preference for group sessions that would provide conviviality, interactivity and support. Participative methods should be used by trained health professionals. Sessions should be ideally proposed not far from home, if possible close to the diagnosis delivery. Education could be delivered by a multidisciplinary team with booster sessions or some kind of follow-up for exercise. The team could include a rheumatologist, dietician, physiotherapist, nurse and occupational therapist for home arrangement and fall prevention. The gynaecologist could have a role in motivating women. Psychological support seemed rarely needed, and all groups doubted the benefit of including partners.

Educational Needs. Specific Men and GIOP (Tables 6, 7)

Men Men did not at first see the interest of PE intervention: information should be given primarily by the doctor. Few men expressed educational needs. However, when answering the follow-up questions by the researchers, they were interested in exercise and wished for more varied educational formats: short and focused messages that could be found in leaflets or on the Internet. Men had more needs regarding knowledge. They were keen to learn about new medications and side effects. Seeking information could help in better choosing treatment. Men partly claimed autonomy. Short programs were preferred and sessions dedicated to men as well as face-to-face patient education.

GIOP Converse to men, GIOP individuals expressed that patient education could palliate the lack of time during consultations or the lack of explanations by the doctor. However, the researchers needed to ask more questions to investigate their specific educational needs on OP, probably because OP was not their prominent disease. As for men, the needs

were to know a lot about OP and new available medications. People with GIOP had a balanced opinion between group PE sessions versus individual PE as well as the interest of being mixed with people with other types of OP.

Discussion

This qualitative study brings information that although some OP patients' experiences and beliefs are common to all types of OP, they may differ by type of OP, especially for people with GIOP and men.

Considering the general beliefs on OP, this study supports the data reported in the literature [24], on OP being considered as a natural consequence of ageing and not a severe disease [19, 20, 24], the relation between fractures and OP being not so clearly identified [18, 19, 40, 41] (except for men in this study). However, in the present study, some participants including PMO women considered OP a severe disease with fear of new fractures, risk of dependence and a negative impact on quality of life, as in the GLOW survey [42]. Unlike some other studies [18, 20], we found that some PMO women reported low mood and impaired self-esteem [27], a feeling of isolation and a lack of understanding by their personal environment.

These two opposite experiences about OP were well synthesized by the systematic review by Barker et al. [24] that aimed to propose a meta-ethnographic model of OP patient experiences; the authors showed that OP could affect patients' biographical integrity in diverse ways according to the disruption of OP fractures.

The important finding of the present study was that the negative impact on mood was not systematically associated with prevalent fractures: some PMO_wf women, although asymptomatic, actually showed the same impaired psychological well-being as PMO_f women.

The interest of the study was the investigation of people with GIOP, which had not been previously studied. We found that knowledge of OP was heterogeneous among GIOP participants, with difficulty in identifying the consequences of OP apart from the causal disease. The impact on mood varied: it was either the burden of an additional disease or a better coping of OP, which was considered a less severe condition than the causal disease. Participants also reported fewer prevention behaviours. Participants regretted that the OP was not diagnosed before the occurrence of the first fracture. This emphasize that a particular attention should be paid to information and coaching of GIOP patients, to help them understand the risk and for better acceptance [43].

The second interest of our study was the investigation of men's perspectives. Men's experiences were consistent with findings from the few available qualitative studies



that OP was a "women's disease" [25–27], which led to difficulties in coping. Men resented the loss of functional capacities because of the impact on the personal and social view of masculinity [25, 26]. However, this study did not find that men had no sense of the risks of OP as described in other studies among men with OP [26], healthy men or men at risk of OP [28–31]: conversely, men had various levels of knowledge but clearly identified the link between OP and the risk of fracture. This study also revealed positive coping behaviours among men. Men at risk of OP were confident in their self-efficacy of undertaking bone healthy behaviours.

Numerous participants of all OP types had doubts about medication efficacy. In agreement with other studies, antiosteoporotic drugs were considered by some participants harmful, burdensome and ineffective [19, 27]. Several participants, particularly men and people with GIOP, had problems not knowing whether the treatments were effective. These 2 groups described efficacy according to the evolution of BMD. Although repeating BMD measurement is not recommended [8], in some cases, it could be an opportunity for physicians to discuss adherence with patients [44].

The final objective of the study was for patients to express their specific educational needs in terms of a suitable content and format of education and to compare these needs by type of OP. Participants did not know about PE interventions. They were interested in non-pharmacological treatments, particularly exercise and learning how to prevent falls, perhaps as a consequence of their mistrust of pharmacological treatments [19, 45]. However, adherent participants also expressed this need, which could be considered positive coping and an attempt at empowerment [11]. This study adds information to the systematic review by Raybould et al. [38] as to the perceived importance of non-pharmacological treatments that could be encouraged and supported in parallel with the information that such treatments should not be used as an alternative to medications [16]. A few misconceptions about diet and type of exercises were mentioned, and some participants wanted clarification on the contradictory information they receive about diet.

Men with OP and people with GIOP had more needs regarding knowledge of OP, new medications and side effects than other participants. Autonomy and shared decision-making about treatments were particularly important for men.

Participants preferred group sessions that could allow for sharing experiences and be conducted by a well-trained multidisciplinary team. Some participants suggested that their general practitioner (GP) could participate in the sessions, which seemed hardly feasible considering physicians' lack of time and that GPs may also have erroneous beliefs and limited knowledge of OP [19]. On the whole, contrary to physicians emphasizing adherence to medication and discussing pharmacological treatments [38], participants wished a holistic management. Again, some differences were found by type of OP because some GIOP patients and men preferred face-to-face sessions and men also advocated other means of information such as short messages, leaflets and the Internet.

The strengths of the study were the investigation of different types of OP patients, especially men and people with GIOP, who were assessed with the same methodology in order to observe similarities and differences, whereas previous studies had addressed men separately from women apart from the study by Merle et al. [27]. We paid special attention to recruitment from various geographical areas and various types of residences. Another strength was the investigation of the patients' opinion on the format of education delivery. Concerning methodology, the study met 16/16 of the Consolidated Criteria for Reporting Qualitative Studies for personal characteristics, investigators' relationship with participants, participant's selection and setting and 9/15 of the criteria for data collection, data analysis and reporting [39].

The study has some limitations. One is related to the recruitment by rheumatologists only, although a large proportion of OP patients are followed in primary care. Although the study sample was large, 53 participants in total, because 4 groups of OP were studied, the number of participants in each group was reduced accordingly, which may have lowered the opportunity to catch some information and differences. The results are valid in a country with a universal coverage healthcare system. During the past years, the media has had a negative impact on OP management in France, with controversies on drug usefulness and side effects and promoting the idea that OP is not a disease. Other cultures and medical systems might reveal differences. Finally, by selecting participants who were prone to participate in focus groups, the study may have overestimated preferences for group education.

In conclusion, patients' beliefs about OP are diverse, and OP should not be considered a trivial disease but also a condition that may have a high impact on mood and quality of life, even among people without fractures. The present study highlights the similarities and differences of the experiences and needs in specific populations with OP such as men or people with GIOP.

Perspectives for Educational Approaches

- Specific populations with osteoporosis such as men or people with GIOP need particular management because they have distinct experiences and needs.
- Assessment of patients' needs should be personalized to improve osteoporosis management.



It would be of interest to propose group sessions in educational interventions to allow for sharing experiences but also face-to-face education and brief information including via the Internet towards particular populations such as men or people with GIOP.

Acknowledgements We thank the patients who participated in the study and all members of the SOLID'OS group.

Members of the SOLID'OS group: rheumatologists: C. Beauvais, B. Cortet, L. Euller Ziegler, E. Lespessailles, F. Levy Weil, D.Poivret, AC Rat, M. Rousière, C. Thévenot, P. Grandhaye; Nurses: D. Aubraye, M. Beranger, F. Nominé; patients association: AFLAR: C. Cardon, L. Carton; occupational therapist: N. Dechassat; dietician: A.Hector.

Author Contributions CB and ACR designed the study, analysed the data and prepared the first and final draft of the paper. They are guarantors. Authors DP, EL, CT, LEZ and MB and FL-W participated in the study design and protocol. Authors DP, EL, CT, LEZ, MR, BC and ACR contributed to the experimental work by selecting patients and collecting data. Authors SG, KL, YM performed the interviews and qualitative analysis. BC reviewed the first and final draft of the paper. All authors revised the paper critically for intellectual content and approved the final version. All authors agree to be accountable for the work and to ensure that any questions relating to the accuracy and integrity of the paper are investigated and properly resolved.

Funding This study was funded by the French Society of Rheumatology (SFR). The SFR received an unrestricted institutional grant from Amgen and Lilly for research in the field of osteoporosis and education. Lilly and Amgen were informed that part of the funding would be allocated to this study. Lilly and Amgen did not intervene in the choice of the study's subject, design, data collection or decision to publish. The grant was used to pay the researchers. All other authors did not receive any honoraria for this study and have no disclosure of interest.

Compliance with Ethical Standards

Conflict of interest Catherine Beauvais, Didier Poivret, Eric Lespessailles, Yves Magar, Corinne Thevenot, Liana Euller Ziegler, Sophie Gendarme, Karine Legrand, Edith Filaire, Dominique Aubraye, Martine Beranger, Mickael Rousière, Florence Lévy-Weil, Bernard Cortet, Anne Christine Rat declare that they have no conflict of interest.

Human and Animal Rights and Informed Consent Participants were informed of the study objectives and schedule of the study. Informed consent was obtained from all individual participants included in the study according to local recommendations on research involving human participants.

References

- Wade SW, Strader C, Fitzpatrick LA et al (2014) Estimating prevalence of osteoporosis: examples from industrialized countries. Arch Osteoporos 9:182. https://doi.org/10.1007/s1165 7-014-0182-3
- Alswat KA (2017) Gender disparities in osteoporosis. J Clin Med Res 9:382–387. https://doi.org/10.14740/jocmr2970w

- Qaseem A, Forciea MA, McLean RM et al (2017) Treatment of low bone density or osteoporosis to prevent fractures in men and women: a clinical practice guideline update from the American College of Physicians. Ann Intern Med 166:818–839. https://doi. org/10.7326/M15-1361
- Briot K, Roux C (2015) Glucocorticoid-induced osteoporosis. RMD Open 1:e000014. https://doi.org/10.1136/rmdopen-2014-000014
- Silverman S, Curtis J, Saag K et al (2015) International management of bone health in glucocorticoid-exposed individuals in the observational GLOW study. Osteoporos Int J Establ Result Coop Eur Found Osteoporos Natl Osteoporos Found USA 26:419–420. https://doi.org/10.1007/s00198-014-2883-2
- Kanis JA, Cooper C, Rizzoli R et al (2018) European guidance for the diagnosis and management of osteoporosis in postmenopausal women. Osteoporos Int J Establ Result Coop Eur Found Osteoporos Natl Osteoporos Found USA. https://doi.org/10.1007/ s00198-018-4704-5
- Lems WF, Dreinhöfer KE, Bischoff-Ferrari H et al (2017) EULAR/EFORT recommendations for management of patients older than 50 years with a fragility fracture and prevention of subsequent fractures. Ann Rheum Dis 76:802–810. https://doi. org/10.1136/annrheumdis-2016-210289
- Briot K, Roux C, Thomas T et al (2018) 2018 update of French recommendations on the management of postmenopausal osteoporosis. Jt Bone Spine Rev Rhum 85:519–530. https://doi. org/10.1016/j.jbspin.2018.02.009
- Buckley L, Guyatt G, Fink HA et al (2017) 2017 American College of Rheumatology guideline for the prevention and treatment of glucocorticoid-induced osteoporosis. Arthritis Care Res 69:1095–1110. https://doi.org/10.1002/acr.23279
- Briot K, Cortet B, Roux C et al (2014) 2014 update of recommendations on the prevention and treatment of glucocorticoid-induced osteoporosis. Jt Bone Spine Rev Rhum 81:493–501. https://doi.org/10.1016/j.jbspin.2014.10.001
- Huas D, Debiais F, Blotman F et al (2010) Compliance and treatment satisfaction of post menopausal women treated for osteoporosis. Compliance with osteoporosis treatment. BMC Womens Health 10:26. https://doi.org/10.1186/1472-6874-10-26
- Cotté F-E, Fardellone P, Mercier F et al (2010) Adherence to monthly and weekly oral bisphosphonates in women with osteoporosis. Osteoporos Int J Establ Result Coop Eur Found Osteoporos Natl Osteoporos Found USA 21:145–155. https://doi.org/10.1007/ s00198-009-0930-1
- Freiberger E, Kemmler W, Siegrist M, Sieber C (2016) Frailty and exercise interventions: evidence and barriers for exercise programs. Z Gerontol Geriatr 49:606–611. https://doi.org/10.1007/ s00391-016-1134-x
- Weaver J, Sajjan S, Lewiecki EM, Harris ST (2017) Diagnosis and treatment of osteoporosis before and after fracture: a side-by-side analysis of commercially insured and medicare advantage osteoporosis patients. J Manag Care Spec Pharm 23:735–744. https:// doi.org/10.18553/jmcp.2017.23.7.735
- Yeam CT, Chia S, Tan HCC et al (2018) A systematic review of factors affecting medication adherence among patients with osteoporosis. Osteoporos Int 29:2623–2637. https://doi.org/10.1007/ s00198-018-4759-3
- Schousboe JT (2013) Adherence with medications used to treat osteoporosis: behavioral insights. Curr Osteoporos Rep 11:21–29. https://doi.org/10.1007/s11914-013-0133-8
- Clark EM, Gould VC, Tobias JH, Horne R (2016) Natural history, reasons for, and impact of low/non-adherence to medications for osteoporosis in a cohort of community-dwelling older women already established on medication: a 2-year follow-up study. Osteoporos Int 27:579–590. https://doi.org/10.1007/s00198-015-3271-2



- Besser SJ, Anderson JE, Weinman J (2012) How do osteoporosis patients perceive their illness and treatment? Implications for clinical practice. Arch Osteoporos 7:115–124. https://doi.org/10.1007/ s11657-012-0089-9
- Alami S, Hervouet L, Poiraudeau S et al (2016) Barriers to effective postmenopausal osteoporosis treatment: a qualitative study of patients' and practitioners' views. PLoS ONE 11:e0158365. https://doi.org/10.1371/journal.pone.0158365
- Lau E, Papaioannou A, Dolovich L et al (2008) Patients' adherence to osteoporosis therapy: exploring the perceptions of post-menopausal women. Can Fam Phys Med Fam Can 54:394

 –402
- Salter C, McDaid L, Bhattacharya D et al (2014) Abandoned acid? Understanding adherence to bisphosphonate medications for the prevention of osteoporosis among older women: a qualitative longitudinal study. PLoS ONE 9:e83552. https://doi.org/10.1371/ journal.pone.0083552
- Giangregorio L, Dolovich L, Cranney A et al (2009) Osteoporosis risk perceptions among patients who have sustained a fragility fracture. Patient Educ Couns 74:213–220. https://doi. org/10.1016/j.pec.2008.08.001
- Mazor KM, Velten S, Andrade SE, Yood RA (2010) Older women's views about prescription osteoporosis medication: a cross-sectional, qualitative study. Drugs Aging 27:999–1008. https://doi.org/10.2165/11584790-000000000-00000
- Barker KL, Toye F, Lowe CJM (2016) A qualitative systematic review of patients' experience of osteoporosis using metaethnography. Arch Osteoporos. https://doi.org/10.1007/s1165 7-016-0286-z
- Nielsen DS, Brixen K, Huniche L (2011) Men's experiences of living with osteoporosis: focus group interviews. Am J Mens Health 5:166–176
- Solimeo SL (2011) Living with a 'women's disease': risk appraisal and management among men with osteoporosis. J Mens Health 8:185–191. https://doi.org/10.1016/j. jomh.2011.06.001
- Merle B, Dupraz C, Haesebaert J et al (2018) Osteoporosis prevention: where are the barriers to improvement in a French general population? A qualitative study. Osteoporos Int J Establ Result Coop Eur Found Osteoporos Natl Osteoporos Found USA. https://doi.org/10.1007/s00198-018-4720-5
- Wong CP, Lok MK, Wun YT, Pang SM (2014) Chinese men's knowledge and risk factors of osteoporosis: compared with women's. Am J Mens Health 8:159–166. https://doi.org/10.1177/15579 88313503981
- Babatunde OT, Marquez S, Taylor A (2017) Osteoporosis knowledge and health beliefs among men in midlife years. J Nutr Educ Behav 49:759–763.e1. https://doi.org/10.1016/j.jneb.2017.05.346
- Hsieh E, Fraenkel L, Bradley EH et al (2014) Osteoporosis knowledge, self-efficacy, and health beliefs among Chinese individuals with HIV. Arch Osteoporos. https://doi.org/10.1007/s1165 7-014-0201-4
- Lassemillante A-CM, Skinner TL, Hooper JD et al (2017) Osteoporosis-related health behaviors in men with prostate cancer and survivors: exploring osteoporosis knowledge, health beliefs, and self-efficacy. Am J Mens Health 11:13–23. https://doi. org/10.1177/1557988315615956
- Solomon DH, Iversen MD, Avorn J et al (2012) Osteoporosis telephonic intervention to improve medication regimen adherence: a large, pragmatic, randomized controlled trial. Arch Intern Med 172:477–483. https://doi.org/10.1001/archinternmed.2011.1977

- Schousboe JT, Debold RC, Kuno LS et al (2005) Education and phone follow-up in postmenopausal women at risk for osteoporosis: effects on calcium intake, exercise frequency, and medication use. Dis Manag Health Outcomes 13:395

 –404
- Clowes JA, Peel NFA, Eastell R (2004) The impact of monitoring on adherence and persistence with antiresorptive treatment for postmenopausal osteoporosis: a randomized controlled trial.
 J Clin Endocrinol Metab 89:1117–1123. https://doi.org/10.1210/jc.2003-030501
- Jeihooni AK, Hidarnia A, Kaveh MH et al (2015) Effects of an osteoporosis prevention program based on health belief model among females. Nurs Midwifery Stud 4:e26731. https://doi. org/10.17795/nmsjournal26731
- Nielsen D, Ryg J, Nielsen W et al (2010) Patient education in groups increases knowledge of osteoporosis and adherence to treatment: a two-year randomized controlled trial. Patient Educ Couns 81:155–160. https://doi.org/10.1016/j.pec.2010.03.010
- WHO Working Group (2010) Therapeutic patient education continuing education programmes for health care providers in the field of prevention of chronic diseases. Report of a WHO Working Group 1998. http://www.euro.who.int/document/e63674.pdf. Accessed 29 Mar 2010
- Raybould G, Babatunde O, Evans AL et al (2018) Expressed information needs of patients with osteoporosis and/or fragility fractures: a systematic review. Arch Osteoporos. https://doi. org/10.1007/s11657-018-0470-4
- Tong A, Sainsbury P, Craig J (2007) Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care J Int Soc Qual Health Care 19:349–357. https://doi.org/10.1093/intqhc/mzm042
- Sale JEM, Gignac MA, Frankel L et al (2012) Patients reject the concept of fragility fracture—a new understanding based on fracture patients' communication. Osteoporos Int 23:2829–2834. https://doi.org/10.1007/s00198-012-1914-0
- Siris ES, Gehlbach S, Adachi JD et al (2011) Failure to perceive increased risk of fracture in women 55 years and older: the Global Longitudinal Study of Osteoporosis in Women (GLOW). OsteoporosInt 22:27–35
- 42. Roux C, Wyman A, Hooven FH et al (2012) Burden of non-hip, non-vertebral fractures on quality of life in postmenopausal women: the Global Longitudinal study of Osteoporosis in Women (GLOW). Osteoporos Int J Establ Result Coop Eur Found Osteoporos Natl Osteoporos Found USA 23:2863–2871. https://doi.org/10.1007/s00198-012-1935-8
- Tory HO, Solomon DH, Desai SP (2015) Analysis of quality improvement efforts in preventing glucocorticoid-induced osteoporosis. Semin Arthritis Rheum 44:483–488. https://doi.org/10.1016/j.semarthrit.2014.09.011
- Winzenberg T, Oldenburg B, Jones G (2010) Bone density testing: an under-utilised and under-researched health education tool for osteoporosis prevention? Nutrients 2:985–996. https://doi. org/10.3390/nu2090985
- 45. Sale JEM, Gignac MA, Hawker G et al (2014) Non-pharmacological strategies used by patients at high risk for future fracture to manage fracture risk—a qualitative study. Osteoporos Int 25:281–288. https://doi.org/10.1007/s00198-013-2405-7

Publisher's Note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.



Affiliations

Catherine Beauvais 1 \odot · Didier Poivret 2 · Eric Lespessailles 3 · Corinne Thevenot 4 · Dominique Aubraye 5 · Liana Euller Ziegler 6 · Martine Beranger 3 · Edith Filaire 7,8,9 · Sophie Gendarme 10 · Karine Legrand 10 · Yves Magar 11 · Mickael Rousière 1 · Florence Lévy-Weil 5 · Bernard Cortet 12 · Anne Christine Rat 13,14 · SOLID'OS Working Group

- Rheumatology Department, Hôpital Universitaire Saint Antoine, APHP, Paris, France
- Rheumatology Department, Centre Hospitalier régional Metz-Thionville, Thionville, France
- Rheumatology Department, Centre Hospitalier Régional, Orléans La Source, France
- ⁴ Rheumatology Department, Centre Hospitalier, Laon, France
- ⁵ Rheumatology Department, Centre Hospitalier Victor Dupouy, Argenteuil, France
- ⁶ Rheumatology Department, Hôpital Universitaire Pasteur 2, Nice, France
- CIAMS, Universite Paris Sud, Université Paris-Saclay, Orsay Cedex, France
- 8 CIAMS, Université d'Orleans, Orleans, France

- ⁹ INRA, UNH, Unite de Nutrition Humaine, CRNH Auvergne, Université Clermont Auvergne, Clermont-Ferrand, France
- Centre Hospitalier régional Universitaire de Nancy, INSERM, CIC Epidémiologie clinique, Nancy, France
- Edusanté, Vanves, France
- Centre Hospitalier Universitaire C.H.U. Lille and Université Lille 2, Rheumatology Department and EA 4490, 59000 Lille, France
- ¹³ Université de Lorraine, APEMAC, 54000 Nancy, France
- CHU Caen Rheumatology Department, INSERM, CHRU Nancy, CIC 1433 Epidémiologie clinique, Caen, France

