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**Comparative-Effectiveness Research** 

# Barriers and Expectations for Patients in Post-Osteoporotic Fracture Care in France: The EFFEL Study

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# ABSTRACT

*Objectives:* This study aimed to quantify the relative importance of barriers to better secondary prevention of osteoporotic fractures and of care expectations expressed by patients with osteoporotic fractures in France.

*Methods:* A qualitative exploration of potential barriers to care and expectations was undertaken through a systematic literature review and in-depth patients interviews. A list of 21 barriers and 21 expectations was identified. These were presented to 324 subjects with osteoporotic fractures, identified in a representative sample of the French population, in the form of best-worst scaling questionnaires. Patients rated the relative importance of the attributes, and arithmetic mean importance scores were calculated and ranked. A Bayesian hierarchical model was also performed to generate a relative importance score. Latent class analysis was performed to identify potential subgroups of patients with different response profiles.

*Results:* A total of 7 barriers were rated as the most important, relating to awareness of osteoporosis and coordination of care. The highest-ranked barrier, "my fracture is not related to osteoporosis," was significantly more important than all the others (mean importance score 0.45; 95% confidence interval 0.33-0.56). A similar ranking of attributes was obtained with both the arithmetic and the Bayesian approach. For expectations, no clear hierarchy of attributes was identified. Latent class analysis discriminated 3 classes of respondents with significant differences in response profiles (the educated environmentalists, the unaware, and the victims of the system).

*Conclusions:* Better quality of care of osteoporosis and effective secondary fracture prevention will require improvements in patient education, training of healthcare professionals, and coordination of care.

*Keywords:* attribute identification, best-worst scaling, fracture, latent classes analysis, osteoporosis, preference elicitation methods, secondary prevention.

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# Introduction

The gap between best standards of care for osteoporotic fractures and everyday practice has been demonstrated in many different countries and healthcare systems.<sup>1-6</sup> In particular, 70% to 80% of victims from a first fracture do not undergo further investigation and do not benefit from any antiosteoporosis treatment.<sup>7</sup> This is of concern because of the risk of refracture after an osteoporotic fracture<sup>8,9</sup> and the elevated mortality risk after certain types of fracture.<sup>5,10-12</sup> Effective and timely treatment can significantly reduce the risk of refracture.<sup>13</sup>

Thus, narrowing this gap and improving standards of care are important public health challenges, which require a clear vision of the barriers that prevent patients receiving the quality of care that is recommended in practice guidelines.<sup>14</sup> Barriers to a better standard of care may exist at the level of the organization of care,<sup>7,15,16</sup> of

physician knowledge and attitudes,<sup>17-19</sup> or of patient perceptions.<sup>20,21</sup> Although the first 2 levels have been widely studied, there is relatively little information available and, in particular, quantitative information on patient perspectives.

The aim of the Etude Fracture Freins et Leviers study was to give voice to patients with osteoporotic fractures so that they could share their experiences and their expectations for change and thus to identify priorities for improving healthcare provision. This report presents information on the identification and relative importance of the barriers to secondary prevention as perceived through patient experience using the best and worst scaling (BWS) method.

## **Methods**

Individuals who had experienced an osteoporotic fracture were asked to rank barriers to care and expectations for secondary

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osteoporosis prevention using the BWS method, a quantitative preference elicitation method.  $^{\rm 22-24}$ 

## Analytical Framework: BWS Method

The BWS method draws its strength from theories of consumer behavior theories, in particular the Thurstone pair comparison law method<sup>25</sup> and McFadden's random utility theory.<sup>26</sup> A total of 3 distinct types of BWS have been developed, namely, the object case (case 1), the profile case (case 2), and the multiprofile case (case 3). In case 1, respondents are invited to select from a list the options that they considered the most important (best) and the one they considered the least important (worst). This type of BWS is mainly intended to assess respondents' preferences among different objects. In case 2, respondents are invited to make choices among different modalities of the object's attributes. This type of BWS allows comparison of the usefulness of attribute modalities, but not the relative importance of the attributes themselves. In case 3, sets of multiple profiles of attributes and their modalities are presented and respondents are invited to choose the best and the worst from each choice set. In cases 1 and 2, no trade-off is involved in these approaches, and as noted by Coast et al,<sup>27</sup> "it is more the value than the preference that is elicited." Only case 3 is based on explicit trade-offs and thus meets the welfarist requirement. The object case approach was adopted in the present study.

# **Generation of Attributes for BWS Evaluation**

The attributes to be evaluated in the study were selected using an iterative process, as recommended by Coast et al.<sup>28</sup> First, a systematic literature review was performed following the 2009 Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines.<sup>29</sup> This review identified 193 publications discussing barriers to treatment and expectations in osteoporosis. These included 2 previous systematic reviews of the same topic.<sup>30,31</sup> The search strategy performed, and a flow chart are provided in the Appendix 1 in Supplemental Materials found at https://doi.org/10.1016/j.jval.2021.10.005.

In the next step, a purposive sample of 24 patients who had experienced a hip fracture, a vertebral fracture, or a limb fracture was identified by the French patient association (Association Française de Lutte Antirhumatismale). The goal was to recruit a broad patient sample to capture in-depth as wide a range of individual patient experience as possible and to minimize the chances that important themes were missed. The sample consisted of 24 women aged between 53 and 88 years, of whom 17 were aged < 75 years at the time of the interview. The subjects came from different occupational classes (before retirement). All had experienced a recent osteoporotic fracture (8 cases each of hip, vertebral, and limb fractures). A total of 10 women were taking a specific antiosteoporosis treatment.

The use of semistructured individual interviews to identify attributes relating to the perceptions and concerns of individual patients with osteoporosis followed a similar principal to that previously reported by Coast and Horrocks,<sup>32</sup> although in the present case, interviews were conducted in parallel rather than iteratively. Semistructured interviews of these 24 patients were conducted from July 2018 to September 2018 by a team of trained sociologists using an interview grid established from the literature review. Interviews were transcribed and a content analysis was performed on the collected verbatim to identify attributes that could be tested in the quantitative phase. This content analysis was performed by independent social scientists experienced in this type of analysis. No formal coding system was used, and no prespecified semantic or syntactic rules on how the attributes

should be formulated were applied. These attributes were then grouped by theme by the data analyst. Themes were not identified in advance.

From these in-depth interviews, 42 attributes related to 21 potential barriers and 21 expectations for care were identified. These clustered into 5 major themes, namely, attributes relating to subjects' attitudes toward their own health status, to representations of osteoporosis, to perceptions of the effectiveness and safety of treatments, to interactions with healthcare professionals, and to the functioning of the healthcare system. The study's Steering Committee assessed the list of attributes selected and validated that they were relevant to the goals of the study. The identified barriers and expectations are presented by theme in Appendix 2 in Supplemental Materials found at https://doi.org/10.1016/j. jval.2021.10.005. A large number of expectations related to the functioning of the care pathway (9 of 21), whereas only 3 barriers were identified for this theme. Examples of verbatim are presented in Appendix 2 in Supplemental Materials found at https:// doi.org/10.1016/j.jval.2021.10.005.

#### Design of the BWS Questionnaire

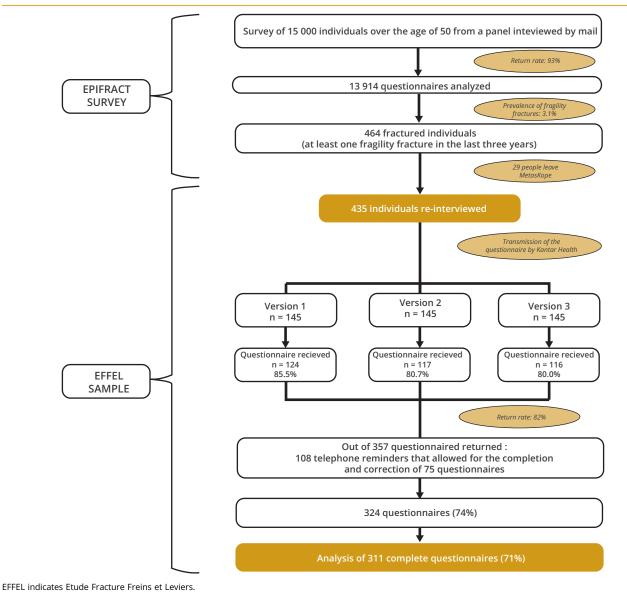
Two sets of test attributes were built using a balanced incomplete blocks design,<sup>33</sup> one for barriers and one for expectations. Each of the attributes appeared on average 5 times across the choice sets, and each attribute pair was presented once on average. Given that the number of attributes in each choice set was less than the total number of attributes to be ranked, the blocks were incomplete. The design was balanced so that each item was presented the same number of times (frequency balance), the order of presentation did not differ between items (position balance), the number of times each pair of items was presented was the same for all pairs (orthogonal balance), and there was no correlation between the presentations of pairs of items (pair independence).

To reduce the cognitive burden for respondents, 3 different versions of the questionnaire were prepared, each with 7 items for barriers and 7 items for expectations, covering between them the full range of choice sets. The 3 questionnaires were randomly assigned to respondents, each of whom completed a single questionnaire. A sample item from the questionnaire is provided in Appendix 3 in Supplemental Materials found at https://doi.org/10.1016/j.jval.2021.10.005.

# **Data Collection**

A postal survey was addressed to a representative sample of 20000 households from the general French population (Metaskope, TNS Sofres), built using the quota method. Subjects were asked whether they had experienced a fracture in the previous 3 years. Subjects responding that this was not the case terminated the questionnaire at this point. The remaining subjects then answered a further series of questions on the nature of the fracture, fracture management, quality of life, risk factors, and osteoporosis. For subjects who had experienced > 1 fracture, they were asked to document each, up to a maximum of 3. Fragility fractures were distinguished from other types of fracture as previously described, based on the circumstances in which the fracture had occurred.<sup>34</sup> In addition, fractures of the feet, hands, or nose were not considered to be fragility fractures. Fragility fractures were then subdivided into major and minor fractures. Fractures to the shoulder, vertebrae, pelvis, hip, or femur and concurrent fracture of 3 or more ribs were considered to be major fractures, these being associated with increased mortality.35

Figure 1. Study flow chart.



#### **Statistical Analysis**

A descriptive analysis, a Bayesian hierarchical analysis and a latent class analysis were performed on the data collected.

For the descriptive analysis, a count analysis was conducted to examine the choice frequency. Two arithmetic prioritization scores were calculated.<sup>36,37</sup> For each item, an importance score was computed by subtracting the number of times the item was chosen as the least important from the number of times it was deemed most important. A positive importance score indicates that the item was more often chosen as "best" rather than "worst," and a negative score indicates the reverse. A null score indicates that the item was considered best as often as worst or that none of the panelists ever chose it as best or worst. The mean importance score was then calculated by dividing the individual importance scores by the number of respondents. This metric can be ranked on an interval scale to display the hierarchy of importance attached to each item. An elevated mean importance individual score, combined with a low coefficient of variation, indicates a strong consensus within the group.

Exploring individual heterogeneity in participants' experience is an important aspect of qualitative research. Although frequentist models are often used to describe the overall experience, Bayesian hierarchical models are, from a methodological point of view, preferable for highlighting interindividual differences. In this approach, a multilevel statistical model is constructed to bring to light latent features underlying the responses provided. The upper level represents utility values at the general population level, and the lower level takes into account individual choices declaring preferences. For each attribute, an average relative importance score (RIS) is calculated with its confidence interval (CI). Individual preference estimates allow any patterns in the variance to be identified, because the parameters are estimated individually rather than aggregated for an "average" participant.

Segmentation of patients was performed using latent class analysis<sup>38,39</sup> to identify classes of participants who provided similar patterns of priorities. This approach uses a maximum likelihood method to identify the number of classes, which provide maximal interclass differences and minimal intraclass differences. This method allows estimation of the probability of belonging to a class independently of any relationship between pairs of items and can thus be used to identify differences in preferences between classes that cannot be observed directly.<sup>40</sup>

Only patients for whom both questionnaires were complete for all item-pairs were included in the latent class analysis. The classes were constructed based on the mean importance scores attributed to the barriers. The goodness of fit of the final model was assessed using the consistent Akaike information criterion. The Bayesian information criterion, log-likelihood criterion, percentage certainty criterion, and relative chi-square were also estimated. An analysis of variance was performed to identify any individual mean importance scores, which differed significantly between classes. A post hoc analysis using the Tukey honest significant difference test was then performed to determine whether overall group averages differed significantly between classes.

The different versions of the questionnaire were programmed in R software and then validated using Sawtooth software (Sawtooth Software, Inc, 2013). No restrictions on choice pairing were imposed during drafting of the questionnaire. The latent class analysis was also performed with Sawtooth software. All the other statistical analyses were performed using SAS version 9.4 and Excel 2016.

## **Ethics**

Analyses performed using the Metaskope panel have been approved by the French Data Protection Agency (declaration no. 1793465). In addition, before answering the questionnaire, panelists provided an informed consent.

#### Results

#### **Study Population**

The study questionnaire was sent to the 464 Metaskope panelists reporting at least 1 osteoporotic fracture. A total of 29 individuals declined to respond. Overall, 357 questionnaires were returned. A follow-up telephone call was made to 108 panelists to correct potential errors or replace missing data in the questionnaires, for example, when a respondent ticked an item as "most important" but did not choose a "least important" item (or vice versa). Corrections were made for 75 questionnaires, and in total, 324 questionnaires could be analyzed. The flow of participants is illustrated in Figure 1, and their characteristics are presented in Table 1. Each of the 3 variants of the questionnaire was completed by the same number of respondents, and no significant differences in patent characteristics were observed between versions. For 13 panelists, certain item pairs were not rated and these were excluded from the latent class analysis. The final analysis was in consequence performed using the data from 311 questionnaires.

# **Results of the BWS Survey**

#### Barriers to better care

The absolute and relative importance of the barriers are presented as mean importance scores in Table 2 and graphically in Figure 2 in the form of a forest plot. For 7 barriers, the score was significantly higher than zero, indicating that these barriers were considered to be serious obstacles by panelists. Barrier 6 "my fracture is unrelated to the osteoporosis" stood out as being the most important. The CIs of this barrier did not overlap with any of those of the 18 lowest ranked barriers. The position of respondents concerning their 3 first priorities was relatively homogeneous with coefficients of variation ranging between 2.5 **Table 1.** Characteristics of panelists participating in the quantitative phase.

Variables	n (%)
Age 50-60 years 61-70 years 71-80 years ≥ 81 years	64 (20.6) 137 (44.1) 72 (23.2) 38 (12.2)
Sex Men Women	69 (22.2) 242 (77.8)
Occupation, Agricultural worker Tradesman or craftsman Professional occupations Managerial White-collar worker Blue-collar worker Never worked	5 (1.6) 13 (4.2) 34 (10.9) 93 (29.9) 123 (39.6) 35 (11.3) 8 (2.6)
Place of residence Rural community (< 2000 inhabitants) Small town (2000-20 000 inhabitants) Large town (20 000-100 000 inhabitants) Large city (> 100 000 inhabitants) Parisian conurbation	62 (19.9) 55 (17.7) 51 (16.4) 95 (30.6) 48 (15.4)
Type of fracture Proximal humerus Distal humerus Forearm/wrist Ribs Vertebra Pelvis Hip Femur Tibia/fibula Ankle Elbow Knee Patella	$\begin{array}{c} 38 \ (12.2) \\ 26 \ (8.4) \\ 88 \ (28.3) \\ 19 \ (6.1) \\ 28 \ (9.0) \\ 13 \ (4.2) \\ 15 \ (4.8) \\ 6 \ (1.9) \\ 20 \ (6.4) \\ 47 \ (15.1) \\ 4 \ (1.3) \\ 5 \ (1.6) \\ 2 \ (0.6) \end{array}$

and 3. The other barriers with a score significantly higher than zero were barriers 21, 2, 14, and 13, all of which relate to dysfunctions of the healthcare system.

For 8 barriers 3, 4, 7, 10, 11, 15, 16, and 18, the score was significantly lower than zero, indicating that these were considered to be less important by panelists. The least important obstacle was barrier 16 "I do not have any psychological support for the management of my osteoporosis." The CI for this barrier did not overlap with the 17 highest-ranked barriers, indicating that it was significantly less important.

In the Bayesian analysis, the average RIS of the 21 barriers was 4.762. A total of 3 barriers 1, 6, and 19 stand out from all others and score above the average RIS, consistent with the findings of the descriptive analysis. The RIS of these 3 barriers is > 1.7 times higher than the average RIS, and barrier 6 (the most important) is estimated to be 3.5 times higher than barrier 16 (the least important).

#### Expectations for better care

The absolute and relative importance of the expectations for care are presented as mean importance scores in Table 3 and graphically in Appendix 4 in Supplemental Materials found at https://doi.org/10.1016/j.jval.2021.10.005. Compared with the barriers, the number of expectations considered important

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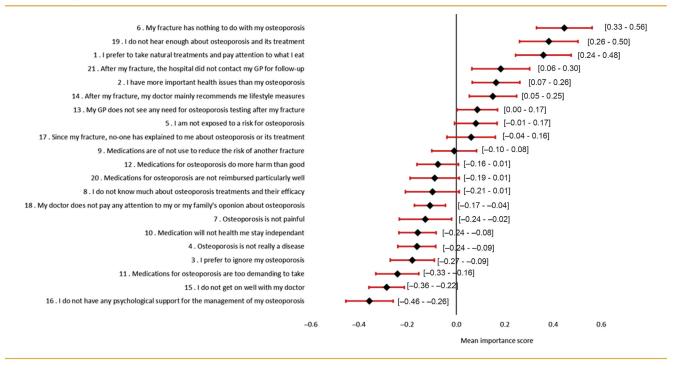
Table 2.	Attributes of	of barriers to	better care	: ranking a	and B-W scores.
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ltem	Ranking	king Barriers (N = 311)	B-W scores				Heterogeneity		
			В	W	B-W score	Mean B-W score	SD	95% CI	CV
6	1	My fracture has nothing to do with my osteoporosis.	224	85	139	0.45	1.04	0.33 to 0.56	2.32
19	2	l do not hear enough about osteoporosis and its treatment.	229	110	119	0.38	1.09	0.26 to 0.5	2.85
1	3	l prefer to take natural treatments and pay attention to what l eat.	203	91	112	0.36	1.04	0.24 to 0.48	2.89
21	4	After my fracture, the hospital did not contact my GP for follow-up.	164	107	57	0.18	1.08	0.06 to 0.3	5.87
2	5	l have more important health issues than my osteoporosis.	118	67	51	0.16	0.88	0.07 to 0.26	5.39
14	6	After my fracture, my doctor mainly recommends me lifestyle measures.	130	83	47	0.15	0.88	0.05 to 0.25	5.82
13	7	My GP does not see any need for osteoporosis testing after my fracture.	98	71	27	0.09	0.75	0 to 0.17	8.70
5	8	l am not exposed to a risk of osteoporosis.	100	75	25	0.08	0.79	-0.01 to 0.17	9.87
17	9	Since my fracture, no one has explained to me about osteoporosis or its treatment.	115	96	19	0.06	0.90	-0.04 to 0.16	14.69
9	10	Medications are of not use to reduce the risk of another fracture.	105	108	-3	-0.01	0.83	-0.1 to 0.08	86.33
12	11	Medications for osteoporosis do more harm than good.	63	87	-24	-0.08	0.77	-0.16 to 0.01	9.99
20	12	Medications for osteoporosis are not reimbursed particularly well.	92	120	-28	-0.09	0.91	-0.19 to 0.01	10.16
8	13	l do not know much about osteoporosis treatments and their efficacy.	121	152	-31	-0.10	1.00	-0.21 to 0.01	10.03
18	14	My doctor does not pay any attention to my or my family's opinion about osteoporosis.	28	62	-34	-0.11	0.58	-0.17 to -0.04	5.31
7	15	Osteoporosis is not painful.	103	143	-40	-0.13	0.98	-0.24 to -0.02	7.58
10	16	Medication will not health me stay independent.	46	96	-50	-0.16	0.70	-0.24 to -0.08	4.33
4	17	Osteoporosis is not really a disease.	52	103	-51	-0.16	0.71	-0.24 to -0.09	4.31
3	18	I prefer to ignore my osteoporosis.	69	126	-57	-0.18	0.82	-0.27 to -0.09	4.48
11	19	Medications for osteoporosis are too demanding to take.	50	126	-76	-0.24	0.80	-0.33 to -0.16	3.28
15	20	I do not get on well with my doctor.	11	101	-90	-0.29	0.66	-0.36 to -0.22	2.27
16	21	l do not have any psychological support for the management of my osteoporosis.	56	168	-112	-0.36	0.89	-0.46 to -0.26	2.46

(lower limit of the 95% Cl > 0) was higher (11 vs 7 items). Nevertheless, these expectations are less structured and the considerable overlap between coefficients of variation precludes unambiguous ranking of the expectations. The 5 most important (expectations 2, 1, 5, 16, and 10) have very similar scores and their 95% Cl overlap with all the other expectations considered

important with the exception of expectation 7. The expectations considered as important relate primarily to the functioning of the healthcare system (expectations 16, 17, 19, and 13) and perceptions of osteoporosis and its treatment (expectations 2, 1, 5, and 3). In particular, many correspond to specific practical improvements (eg, expectations 16 and 5).

Figure 2. Relative importance scores for attributes of barriers to care. Data are presented as forest plots, showing, for each attribute, the relative importance score with its 95% confidence interval.



## Latent Class Analysis

In the latent class analysis, the optimal partitioning of the study sample was into 3 classes. Goodness-of-fit criteria are compared among different numbers of classes, which are presented in Table 4. The consistent Akaike information criterion was lowest for the 3class model, as was the Bayesian information criterion. The percentage certainty criterion and log-likelihood criterion decreased as a function of the number of classes, the decrease being most pronounced between a 2- and a 3-class model (Table 4).

These 3 groups differed with respect to the patterns of importance given to the different barriers of care (Fig. 3). The principal features that distinguished these 3 groups were attitudes to care seeking, perceived awareness of osteoporosis, and expectations with respect to the healthcare system.

#### Class 1 (the educated environmentalists)

Class 1 constitutes 18.3% of the panelists and is represented by individuals who probably understand osteoporosis well. They do not consider lack of awareness about osteoporosis to be an important barrier to the implementation of prevention. For example, they rank barrier 19, which ranks second in the overall population, in last place (Fig. 3). In the second last place, they rank barrier 8. Nevertheless, they consider the gaps in healthcare provision as important barriers (barriers 13, 17, and 21 are all ranked in the top 10). In contrast, they are happy to manage their osteoporosis outside the health system, with barrier 1 ranked as most important.

## Class 2 (the unaware)

Class 2 accounts for 31.1% of the panelists and corresponds to individuals who are not particularly concerned about the risk of osteoporosis. Barrier 5 is ranked fifth in this group (Fig. 3). They do not seem to be aware of the system's failures as they rank barrier 21 (ranked fourth overall) in last place and barrier 17 in

18th place (ninth overall). In contrast, as in the overall group, barrier 19 is ranked second.

#### Class 3 (the victims of the system)

Class 3 accounts for 50.5% of the panelists and corresponds to individuals who are eager for medical management of osteoporosis and mostly encounter barriers related to lack of communication and coordination in care (Fig. 3). Barrier 19 was ranked in first place. Barrier 21 was ranked second and barrier 2 third. In contrast, they did not attach importance to barriers related to medication (barriers 10, 11 and 12), and barrier 1, which ranked in the third place overall, was ranked 17th in this group.

# Discussion

## Summary of the Results

The objective of this study was to identify barriers and expectations related to the management of osteoporosis and to rank these in order of importance to people who experienced osteoporotic fractures. For the barriers, it was possible to rank the items adequately, the 3 most important being the belief that fractures are unrelated to osteoporosis, insufficient information on osteoporosis and its treatments, and a preference for alternative medicine approaches. In terms of response patterns, 3 distinct profiles could be identified. With respect to expectations, the items could not be sufficiently differentiated to generate a useful hierarchy.

We identified 3 profiles of individuals with fractures who had quite different perceptions of the barriers to better fracture management. For example, item 1 (I prefer to take natural treatments and pay attention to what I eat) ranked as most important by class 1 (the educated environmentalists) but only 17th of 21 in class 3 (the victims of the system). In contrast, item 19 (You do not

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	Table 3.	Attributes	of expectations	for better	care: ranking	and B-W scores.
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ltem	Ranking	Expectations (N = 311)	B-W scores				Heterogeneity		
			В	W	B-W score	Mean B-W score	SD	95% CI	CV
1	1	Better awareness of the risks of untreated osteoporosis	149	43	106	0.34	0.77	0.25-0.43	2.27
10	2	Have trust in the doctor who treats my osteoporosis	149	44	105	0.34	0.79	0.25-0.43	2.35
2	3	Maintain my independence by treating my osteoporosis.	145	41	104	0.33	0.81	0.24-0.42	2.41
5	4	Have medications with limited side effects.	143	44	99	0.32	0.80	0.23-0.41	2.52
16	5	For my doctor to propose routine tests for osteoporosis	167	68	99	0.32	0.94	0.21-0.42	2.96
17	6	After a fracture, my doctor follows up my osteoporosis.	150	60	90	0.29	0.89	0.19-0.39	3.07
3	7	Have medications for osteoporosis with proven benefit.	111	38	73	0.23	0.77	0.15-0.32	3.30
19	8	Document my osteoporosis and fracture history in my patient records.	132	68	64	0.21	0.86	0.11-0.3	4.19
13	9	Bone densitometry should be reimbursed better.	138	79	59	0.19	0.96	0.08-0.3	5.06
6	10	Be told about bone capital before having a fracture.	141	84	57	0.18	0.91	0.08-0.28	4.96
7	11	Know about the benefits of physical exercise for my osteoporosis.	121	82	39	0.13	0.82	0.03-0.22	6.53
20	12	Discuss my osteoporosis test and fracture risk results with someone.	98	96	2	0.01	0.85	-0.09 to 0.1	131.59
14	13	Treat osteoporosis in people having many other illnesses.	70	73	-3	-0.01	0.75	-0.09 to 0.07	77.88
18	14	Involve osteopaths or homeopathic practitioners in fracture prevention.	127	150	-23	-0.07	1.07	-0.19 to 0.05	14.52
4	15	Have medications that are taken easily and not too often.	65	110	-45	-0.14	0.77	-0.23 to -0.06	5.33
21	16	Dietary advice from a dietitian on combating osteoporosis	83	163	-80	-0.26	0.95	-0.36 to -0.15	3.70
11	17	My physician takes into account my opinion about treatment.	31	122	-91	-0.29	0.73	-0.37 to -0.21	2.49
12	18	Community nurse visit after a fracture	52	170	-118	-0.38	0.91	-0.48 to -0.28	2.40
9	19	Booklet on osteoporosis and its treatment	45	164	-119	-0.38	0.87	-0.48 to -0.29	2.28
8	20	Talking about osteoporosis in the media	39	237	-198	-0.64	0.97	-0.74 to -0.53	1.52
15	21	My physician should measure my waist circumference regularly.	21	241	-220	-0.71	0.85	-0.8 to -0.61	1.20
B indicates best; Cl, confidence interval; CV, coefficient of variation; W, worst.									

hear enough about osteoporosis and its treatment) was ranked in the last place in class 1 but first in class 3. These important differences in perceptions needed to be taken into account when defining public health strategies for improving the secondary prevention of osteoporosis.

The different statistical methods used produced very similar hierarchies, especially for the lowest- and highest-ranking

barriers. This consistency reinforces the robustness of the findings and suggest that the ranking obtained in not a spurious one reflecting noise in the measurements. Notably, the Bayesian hierarchical analysis takes into account intersubject heterogeneity and estimates scores on an individual scale that reflects personal experience and preferences more closely compared with the descriptive analysis.

#### Table 4. Goodness-of-fit statistics for the latent class analysis.

Number of groups	Log-likelihood	AIC	CAIC	BIC	Relative chi-square
2	-6612.7	13 307.3	13 609.9	13 568.9	19.26
3	-6508.6	13141.2	13 598.6	13 536.6	16.09
4	-6427.0	13 020.0	13 632.5	13 549.5	13.99
5	-6367.9	12943.7	13711.1	13607.1	12.30

AIC indicates Akaike information criterion; BIC, Bayesian information criterion; CAIC, consistent Akaike information criterion.

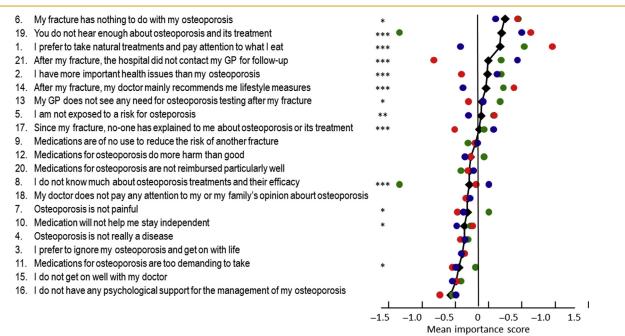
## **Comparison With Previous Studies**

Much qualitative research has been conducted aimed at explaining the gap between best clinical practice and what actually occurs in everyday care.<sup>20,30,31,41-55</sup> These studies have provided much information and identified numerous possible barriers to better care. Nevertheless, these findings are often inconsistent, and this is probably in part attributable to the lack of quantitative hierarchical information on their relative importance and in part, as demonstrated in this study, that different barriers are more or less important for different groups of patients.

Our study confirms that 2 groups of factors seem to contribute to the care gap from the patient's point of view. The first is a lack of understanding of the nature of osteoporosis by patients, who rarely acknowledge any relationship between osteoporosis and fracture (barrier 6 was rated the most important) and perceive the fracture to be "an accident," as has previously been described in studies from North America.<sup>30,52</sup> In a previous study from France,<sup>51</sup> although the most lucid patients accepted that osteoporosis can cause fractures, they still thought that their own fracture was only caused by an accident.<sup>51</sup> The authors pointed out that all patients with osteoporosis share the same erroneous belief, irrespective of how well they are informed about osteoporosis. Referring to osteoporotic fractures as fragility fractures reinforces these beliefs, because patients believe that their fractures are attributable exclusively to an external trauma.<sup>20</sup>

Osteoporosis is frequently not perceived as an illness, because it is imperceptible and lacks clinical manifestations commonly associated with a disease.<sup>42,50</sup> If a fracture does not occur, the lack of symptoms and the limited impact on activities of daily living lead patients to think that they are not ill. In addition, given that the bone is internal and cannot be felt, it is not thought of in terms of health or disease. Similarly, patients do not see the occurrence of a fracture as a sentinel event signaling a high risk of refracture,<sup>52</sup> and such misconceptions may sometimes be encouraged by physicians.<sup>30</sup> For this reason, participants do not consider it necessary to be treated for osteoporosis. They may consider that they do not receive useful and accurate information about treatment and often believe available treatments to be ineffective,

**Figure 3.** Latent class analysis: response patterns of 3 classes of panelists. Items are classed in order of importance in the total population, with the black symbols linked by a black line indicating the mean importance score in the total population. The colored symbols represent the mean scores in the 3 subgroups (green, group 1; red, group 2; blue, group 3). Symbols to the right of the black line indicate items considered relatively more important by members of the group; symbols to the left represent items considered relatively less important. The asterisks indicate statistically significant differences in mean importance scores between groups (\**P*<.05; \*\**P*<.001; \*\*\**P*<.0001).



dangerous, or difficult to take. Several previous studies have also identified some confusion in the minds of fracture victims about the relative benefits of treatments such as calcium and vitamin D supplements and of specific osteoporosis medications.<sup>30,51,53</sup> This may account for the belief of many patients that alternative medicine and healthy lifestyle interventions are the best way to avoid a fracture (barrier 1).

The second group of factors that we identified relates to shortcomings in patient care, with 4 of the 7 barriers whose importance score was significantly higher than zero all relating to dysfunctions of the healthcare system. These shortcomings have been suggested elsewhere to result from segmentation of the healthcare system.<sup>46</sup> In France, the health system is highly compartmentalized with no formal system in place for sharing patients' medical information between specialists. In our study, the lack of communication between the hospital and the general practitioner was highlighted (barrier 21). In practice, the orthopedic surgeon is mostly concerned with acute care and does not have the time or the motivation to ensure long-term follow-up. The poor quality of information sharing between hospital- and community-based physicians regarding patients with osteoporosis has also been reported in studies from Canada and the United States, which have guite different healthcare systems to the French one.<sup>56,57</sup> The general practitioner, who is principally responsible for long-term osteoporosis care, may not have the reflex (or even the knowledge) to explain properly the utility of bone densitometry or treatment and, instead, may suggest ways to improve healthy lifestyle practices and behaviors after a fracture.<sup>30</sup> Both these issues were recognized as important in our survey (barriers 13 and 14). These organizational shortcomings are particularly detrimental to patients with little knowledge of health issues in general and of osteoporosis in particular, who rightly expect a lot from a dialog with their physician. Failure to achieve this may leave the patient confused or encourage them to ignore their disease and to mistrust treatment.

#### **Implications for Health Policies**

The barriers identified in this study provide valuable information for healthcare decision makers from the perspective of people with fractures, which could be used firstly in setting priorities for improving patient education and secondly for developing a comprehensive approach to care.

Patient education in the field of osteoporosis would be the most important objective to pursue. The main challenge for effective secondary prevention of osteoporosis is to re-establish the link between osteoporosis and the fracture by explicitly giving the name "osteoporotic fracture" rather than "fragility fracture." The message to the public should be that the osteoporotic fracture is not an accident. Another important educational goal is to build awareness that effective treatments exist to prevent further fractures. Apart from the direct benefit of increasing patient awareness and knowledge of osteoporosis, this would also have the indirect benefit of facilitating a dialog with the physician, ensuring that the patient asks the right questions, receives satisfactory answers, and takes an active part in therapeutic decision making. In addition, a personalized approach to prevention should be implemented to take into account distinct patient profiles. Although frequently defined on the basis of clinical criteria, these profiles should also reflect the different perceptions, beliefs, and expectations of the patient.

The expectations of each of the 3 identified groups are not the same. The "victims of the system" expect major change and could welcome significant organizational innovations. Experiments in this direction have already taken place in France, notably the establishment of 52 specialized networks, based on the model of the Fracture Liaison Services that pioneered more than 20 years ago in the United Kingdom. The approach adopted with regard to the "unaware group" may be more gradual and should be based essentially on better information for patients and health professionals. The group most likely to resist change will be those who use natural therapies.

Second, training of health professionals about osteoporosis care is fundamental to any effective prevention policy for osteoporotic fracture. Improving physician education is as important as patient education, because failure to talk about osteoporosis, failure to recommend bone densitometry, and failure to propose treatments other than lifestyle measures were identified in this study as important barriers by people with fragility fractures. The principal target of such education should be the healthcare professional in the front line for following up patients after an osteoporotic fracture (in most cases the general practitioner), who should be conscious of the importance of sending the patient for bone densitometry, evaluating fracture risk, and proposing treatments. Guidelines are available worldwide for helping the physician do this appropriately

Finally, a crucial lever for improvement relates to coordination of care among the different healthcare professionals involved. Half the panelists in the study were classed in the "victims of the system" subgroup, who identified poor communication and coordination in healthcare provision as important barriers. In particular, it is important that patients hospitalized for treatment of a fracture be directed to a physician after discharge for detailed evaluation and implementation of an appropriate management plan. This coordination is currently imperfect and could be improved by being more structured. In this respect, fracture liaison services may be of benefit in ensuring continuity of care after an osteoporotic fracture.<sup>16</sup> The "capture the fracture" campaign of the International Osteoporosis Foundation also aims to address this need<sup>46</sup> and has stressed the need to provide specific strategies adapted to different care settings. In particular, the campaign has emphasized the need to identify patients whose fractures are managed in emergency services or directly in the community setting and to ensure that adequate refracture prevention measures are put in place.

#### Strengths and Limitations

The results obtained can be considered robust. The study used a sequential mixed study protocol with a predominance of the quantitative dimension.<sup>56,57</sup> The combined quantitative and qualitative approach provides information on which barriers to care and expectations are the most important with respect to the implementation of a secondary prevention policy for osteoporosis and, above all, allowed the identification of differences among patient subgroups in the perception of the obstacles encountered. Ranking the items was performed using the BWS method, which is more powerful and discriminating than alternative methods such as Likert scales or visual analog scales. The strength of the BWS is that it allows comparisons among attributes to be varied repeatedly, which is not the case for simple ranking or scoring questionnaires, as well as yielding indirect comparisons with all other attributes. In addition, the convergence of the findings of both the arithmetic and the Bayesian approaches argues in favor of the robustness of the barriers identified.

The study has inherent limitations relating to the attributes presented to the panelists. These attributes are not defined specifically, which can lead to different understandings for different individuals. Moreover, no specific rules were set to formulate the

attributes. Therefore, how explicitly these attributes expressed satisfaction or dissatisfaction varied across items. This may have resulted in certain attributes being more difficult to rank than others. In addition, several attributes may refer to overlapping concept (eg, barriers 8 "I do not know much about osteoporosis treatments and their efficacy," 17 "Since my fracture, no one has explained to me about osteoporosis or its treatment," and 19 "You do not hear enough about osteoporosis and its treatment"), which may be difficult to rank. In addition, some aspects of the patient experience may not have been identified during the qualitative

phase of the study. In particular, because only women participated in the qualitative phase, attributes that are important specifically for men may have been neglected.

# Conclusions

Quality of care for people with osteoporotic fractures is clearly suboptimal. Identifying and lowering barriers to care should be an important objective for public health policy. This study has determined the relative importance of a series of barriers to better care cited by people with osteoporotic fractures. From the perspective of these individuals, 2 groups of factors seem to contribute to the care gap in osteoporosis, namely, a lack of understanding of the nature of osteoporosis and shortcomings in the organization of care provision. Nevertheless, perceptions vary among different individuals and this heterogeneity needs to be taken into consideration when deciding healthcare strategies to improve the quality of care in osteoporosis.

#### **Supplemental Material**

Supplementary data associated with this article can be found in the online version at https://doi.org/10.1016/j.jval.2021.10.005.

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