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ORIGINAL ARTICLE

The gaps between patient and physician understanding of the emotional and physical impact of osteoporosis

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Abstract

Summary A multinational survey was conducted to evaluate the gaps between patients and physicians understanding of osteoporosis. The International Osteoporosis Foundation recommends the creation of community-wide patient support programmes to increase prevention and treatment awareness of osteoporosis.

Introduction Osteoporosis is often undiagnosed and untreated, leaving millions of people at risk of debilitating fractures. A survey was designed to investigate any gaps that may exist between physician and patient knowledge of osteoporosis, understand barriers to patient adherence and identify ways to address unmet needs and improve communications.

Methods Telephone interviews were conducted with patients ($n=844$) and physicians ($n=837$) in 13 countries in June/July 2009. Patients were women with postmeno-

pausal osteoporosis currently taking (or in the past 2 years) prescribed medication. Physicians had experience in treating osteoporotic patients, which included only general practitioners who saw ≥ 10 (exception: in Hungary ≥ 5) and specialists who saw ≥ 20 patients with osteoporosis per month.

Results Physicians consistently underestimated their patients' adherence to treatment and beliefs on the impact of osteoporosis on their quality-of-life. Physicians underestimated how many patients worry about breaking a bone (51% vs 79%), as well as patient concerns about declines in activity levels (40% vs 70%), becoming dependent on others (30% vs 60%) and not being able to work for longer (30% vs 57%). Patients believed the most credible osteoporosis information was from specialists (94%). Patients (75%) would like easy to understand materials and 49% would welcome inter-patient discussions of their

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condition. Most physicians (88%) believed that osteoporosis organisations are among the most credible sources for information, 80% would give patients written materials to increase adherence and 76% would recommend patient programmes that encourage better communication on managing osteoporosis.

Conclusion Community-wide patient support programmes may help patients to manage their concerns and address unmet needs in osteoporosis management.

Keywords Osteoporosis · Survey · Patients and physicians · Support programmes · Disease management

Introduction

Osteoporosis is characterised by reduced bone mass and it predisposes a person to an increased risk of fracture [1]. Affecting more than 200 million people worldwide [2], it has become a major health care issue. It results not only in loss of bone mass, but significant problems with respect to functional status and quality of life, including physical, functional and psychosocial impairment, morbidity and mortality [3]. For example, one of the most common outcomes of postmenopausal osteoporosis is vertebral fracture, which can lead to increased pain in normal day-to-day activities thus limiting mobility and social activities, and a reduction in self-confidence due to a loss of stature [4].

The general management of osteoporosis includes the prevention of falls, maintenance of mobility, correction of nutritional deficiencies (calcium, vitamin D and protein) [5] along with prescription medication. The most common current pharmacological options include bisphosphonates, calcitonins, parathyroid hormone, selective oestrogen receptor modulators, strontium ranelate and denosumab [6]. Despite the availability of osteoporosis treatments for more than 10 years, large numbers of osteoporotic fractures still occur and the number is expected to increase [7]. The sites of fractures are varied and of an estimated 9 million new osteoporotic fractures worldwide in 2000, 1.7 million were at the forearm, 1.6 million were at the hip, and 1.4 million were clinical fractures of the vertebrae [8].

Adherence to osteoporosis therapy is often inadequate. Studies show that fewer than 50% of patients are still taking their prescribed medication after 1 year [9]. Inadequate long-term adherence may result in wasted resources, an increased fracture rate and no significant impact on the burden of illness. A recent systematic review of poor adherence to and persistence with osteoporosis medications found that few interventions were efficacious and there was no reported clear trends regarding successful intervention techniques [10]. Potential reasons for non-adherence include misconceptions of personal risk, uncertainty of therapy benefits and

risks, side effects that are too great to tolerate or a belief in the efficacy of lifestyle measures alone [11].

Since osteoporosis outcomes appear to be closely linked to patient beliefs and concerns about the disease and its management, it is essential to gain a better understanding of these issues. The present study aimed to conduct a multinational survey of patients with osteoporosis to (1) investigate gaps that may exist between patient and physician understanding of the emotional and physical impact of osteoporosis, (2) identify barriers to patient adherence to medication, and (3) understand the ways in which osteoporotic patients can better share and receive information about the management and treatment of osteoporosis. To our knowledge, no survey of this scale has been conducted to examine the beliefs of communication of patients towards physicians and vice versa.

Methods

Design

This was a telephone survey to investigate gaps that may exist between physician and patient understanding of osteoporosis, understand barriers to patient adherence, identify unmet needs and improve communications. Structured telephone interviews lasting an average of 15–20 min were conducted over 5 weeks in June and July of 2009 with individuals who agreed to participate. The questionnaire used in the survey was validated by two pilot sessions in Germany and the UK. Within each pilot session, three interviews were conducted to ensure use of the most appropriate wording and optimal logical flow for the survey.

Patient survey

Participants were considered eligible for inclusion in the study if they were female and aged over 55 years, had already gone through the menopause, were diagnosed with postmenopausal osteoporosis by a physician, had visited a physician for osteoporosis and were currently (or in the past 2 years) prescribed medication for osteoporosis.

To achieve a sample size of 80 patients in France, Germany, Italy, Spain, UK and Australia, an average of 1,135 were contacted in each country. To achieve a sample size of 50 patients in Austria, Belgium, Hungary, Greece, Netherlands, Sweden and Switzerland, an average of 1,798 were contacted in each country.

Physician survey

Participants were considered eligible for inclusion in the study if they had 3 to 35 years of experience in treating

patients with osteoporosis, worked mainly in an office-based setting and treated a minimum number of patients suffering from postmenopausal osteoporosis in an average month (at least ten patients for general practitioners/primary care physicians [GPs/PCPs] and at least 20 patients for specialists).

GPs/PCPs and specialists were in a 1:1 ratio for the total number of participants per country; specialists were a country-specific mix of rheumatologists, endocrinologists, gynaecologists and orthopaedists. To achieve a sample size of 80 physicians in Germany, France, Italy, Spain, UK and Australia, an average of 411 per country were contacted. To achieve a sample size of 50 physicians in Austria, Belgium, Hungary, Greece, Netherlands, Sweden and Switzerland, an average of 445 per country were contacted.

Interviews

Interviews were conducted by native speakers of the relevant local language having at least 2 years experience in the medical area. All interviewers were trained by the local fieldwork manager through a personal briefing. Before starting the survey in each country, three to four test interviews were conducted internally to ensure the interviewers' familiarity with the wording and flow of the questionnaire. The questions appeared sequentially so that the interview could not continue until a response was entered for each question; for some questions, an answer of "do not know/no answer" was allowed. Participants in a number of different regions in each country were contacted to ensure that the data were representative.

The interview contained structured questions for patients about the following: socio-demographic information, prescription medication use in the past 2 years, disease history (including diagnosis, symptoms), disease knowledge and physician interaction. The interview contained structured questions for the physicians about the following: their specialty, number of patients with osteoporosis treated, products prescribed and patient education provided.

Data analysis

Data are presented as the percentage of respondents replying to each answer positively. *t* tests were conducted for comparing patient responses with physician responses at 5% risk level (normal averages). However, *t* tests were only performed for those questions that were similar in the patient and the physician questionnaires. Statistical analyses were performed to assess gaps in the answering behaviour of patients and physicians. Quantum or SPSS were used to perform *t* tests on the proportions and means at 5% risk level (differences were considered to be significant at $p < 0.05$).

Results

Sample

Patients

Out of a mean of 1,135 patients contacted in Germany, France, Italy, Spain, UK and Australia, an average of 24% of patients responded. From these, at least 80 eligible patients from each of these countries took part in the survey. The patient response rate for the Netherlands, Austria, Belgium, Hungary, Greece, Sweden and Switzerland was approximately 19%. In these countries, at least 50 eligible patients took part in the survey. The total sample was 844 patients of varied economic and social status (see Table 1)

Table 1 Participants characteristics

Patients on HRT (%)	
Yes	16.0
No	84.0
Education (%)	
Left school with no qualifications	10.4
Primary school	21.1
Secondary school (GCSE/O levels)	38.5
6th form (A levels)	17.3
College/university	10.8
Post graduate	1.2
N/A	0.7
Employed (%)	
Employed	16.4
Unemployed	9.1
Retired	67.9
N/A	6.6
Size of household (%)	
1 person	28.1
2 people	54.7
3 people	10.8
4 people	3.6
5 people+	2.6
N/A	0.2
Monthly household incomes € (%)	
Up to 999	17.9
1,000–1,499	21.2
1,500–1,999	18.2
2,000–2,499	16.5
2,500–2,999	8.6
3,000–3,499	4.0
3,500–3,999	2.1
4,000+	2.4
N/A	9.0

HRT hormone replacement therapy

across the 13 countries, with a minimum of five regions represented per country.

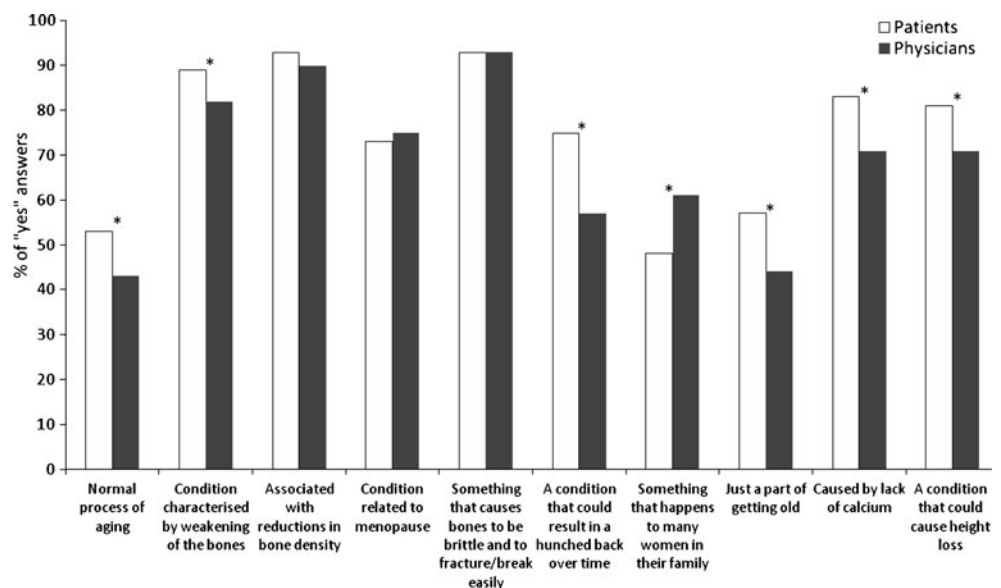
Physicians

Out of a mean of 411 physicians contacted in Germany, France, Italy, Spain, UK and Australia, an average of 49% of physicians responded. From these, at least 80 eligible physicians from each country took part in the survey. The physician response rate for the Netherlands, Austria, Belgium, Hungary, Greece, Sweden and Switzerland was approximately 32%. In these countries, at least 50 eligible physicians from each country took part in the survey. The total sample was 837 physicians (70% men, 30% women) across the 13 countries, with a minimum of five regions represented per country.

Patient and physician knowledge

A total of 69% of patients believed that they were well informed about their disease, with 21% and 48% of patients feeling very knowledgeable and knowledgeable, respectively. Patients understood some of the main aspects of osteoporosis; 93% described osteoporosis as a condition that “causes bones to be brittle and fracture/break easily”, 73% knew that it is a “condition related to the menopause” and 93% that it is “associated with reductions in bone density” (Fig. 1). Patients also described osteoporosis as “just a part of getting old” (57%), “caused by a lack of calcium” (83%) and “a condition that could cause height loss” (81%). Three quarters of patients also described osteoporosis as “a condition that could result in a hunched back over time”. Only 57% of physicians understood osteoporosis in this way.

Fig. 1 Understanding of osteoporosis, % of patients answering “yes” to statements of how they understand osteoporosis compared with % of physicians answering “yes” to statements based on their explanations given to patients about osteoporosis; * $p < 0.05$



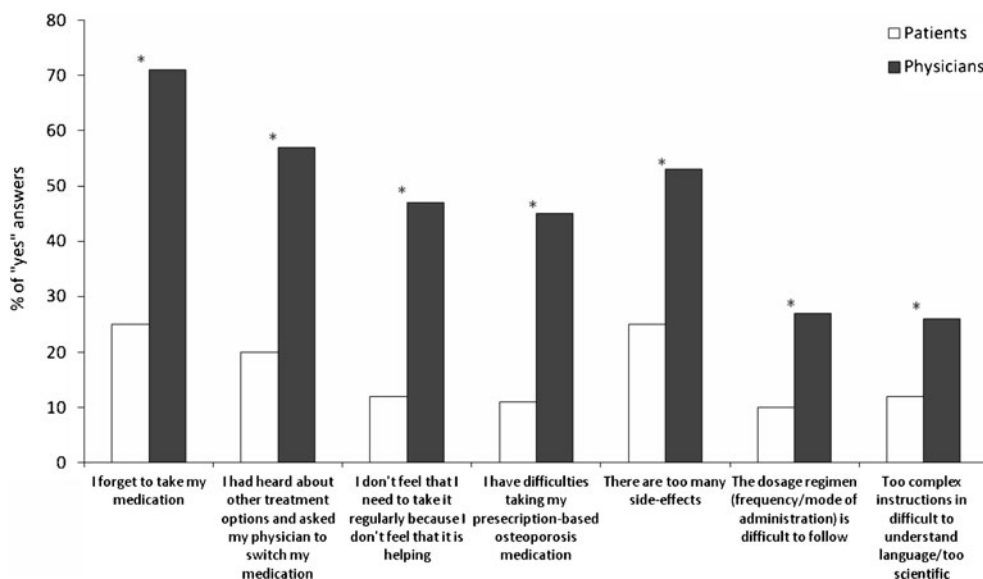
There was a large gap in the assessment of the major risk factors between patients and physicians. Indeed, about one in three patients could not identify any risk factors for osteoporosis compared with 1% in the physician’s group. Patient awareness was low for cortisone therapy (14%), family history of hip fracture (27%) and nicotine use (20%) compared with physician concerns over those risk factors (67%, 79% and 50%, respectively).

Treatment adherence

The physicians’ estimate of the percentage of their patients discontinuing their prescribed osteoporosis medication generally corresponded with their patients’ statements. However, physicians substantially underestimated the average duration of the discontinuation. Whereas patients reported that they discontinued their osteoporosis treatment for an average of 5.5 months, this was 2.6 months longer than the estimation of the physicians ($p < 0.05$). Physicians also estimated that 71% of their patients forgot to take their treatment, while only 25% of patients surveyed admitted to forgetting to take their treatment. Up to 29% of patients did not see a problem in missing a dose once in a while. Reasons patients did not take medication are listed in Fig. 2 and included: wanting to switch to an alternative (20%), the medication is not helping (12%) and too many side effects (25%). Among physicians, 87% indicated that they provided patients with information on the importance of treatment adherence and 82% of the patients reported being informed by their physicians on the importance of taking their treatment continuously.

For patients, the desired features of an osteoporosis treatment included one that works with other medication

Fig. 2 Experiences when taking prescribed osteoporosis medications, % of patients answering “yes” to statements compared with % of physicians answering “yes” to statements based on their beliefs of their patients agreeing to the statements; * $p < 0.05$



being taken (67%), has fewer side effects (58%), needs less frequent dosing (58%), is easier to take (48%), affects daily routine less (43%) and has less complicated dosing (37%). There was a wide disagreement between patients and physicians especially for less complicated dosing, easier to take medication and fewer side effects. The differences between the patients' perspective compared with the physicians perspective were -38%, -36% and -34%, respectively.

Quality of life

Large gaps between the two surveyed groups were reported in attitudes towards the consequences of osteoporosis for patients (Fig. 3). Physicians underestimated patients' concerns about the impact of osteoporosis on their daily life.

Among patients, 70% were afraid that they will not be as active as they would like to be, while physicians estimated this at only 40%. In addition, 60% of patients worried about becoming more dependent on others as a result of their osteoporosis, while physicians estimated this at only 31%. There was no significant difference between patient–physician responses to osteoporosis affecting social life activities and feeling comfortable telling people they have osteoporosis.

Of patients surveyed, 79% were worried about breaking a bone due to their osteoporosis and 57% were afraid of not being able to work for as long as they needed to. Among physicians who were questioned about their patients' beliefs, these were estimated at only 51% and 27%, respectively.

Fig. 3 Attitudes towards osteoporosis, % of patients answering “yes” to statements compared with % of physicians answering “yes” to statements based on their beliefs of their patients agreeing to the statements; * $p < 0.05$

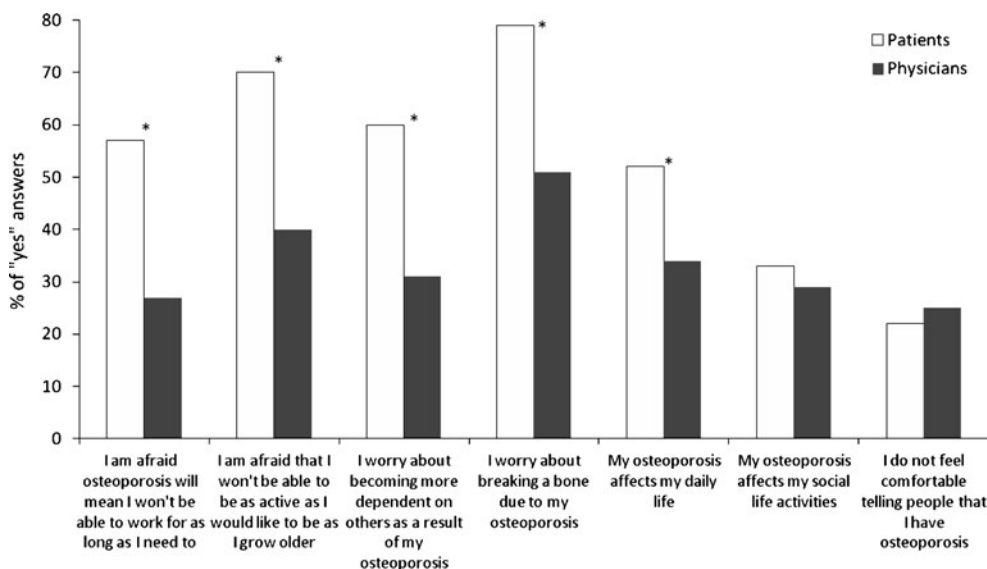


Table 2 Percentage of patients describing what type of support would be helpful in managing osteoporosis

Type of support	Patients (%)
Written information in terms I understand	75
More frequent contact with health care professionals	62
Talking to my friends about osteoporosis personally	60
More readily available/acceptable information from trusted sources offered in my community (i.e., wellness centre, library)	59
A programme that builds my emotional and physical confidence in managing my osteoporosis	58
Better understanding of why I need to take my treatments	50
Opportunities to come together with other people in my community to discuss day-to-day challenges of living with osteoporosis	49

Patient support tools

Patients believed that specialists (94%), GPs (88%) and brochures from osteoporosis organisations (76%) are the most credible sources of information on their osteoporosis. Table 2 shows that 75% of patients wanted to receive written information in terms they understood and 62% of patients would find it helpful to have more frequent contact with their physicians about their osteoporosis. Talking to their friends about osteoporosis helped 60% of patients and 58% of patients requested a programme that builds their emotional and physical confidence in managing their osteoporosis. Almost half of all patients (49%) would welcome opportunities to come together with other people in their community to discuss day-to-day challenges of living with osteoporosis.

Physician support

Table 3 shows that 88% of physicians believed that besides a GP or specialist, brochures from osteoporosis organisations are one of the most credible sources for getting information on osteoporosis. Of the physicians surveyed, 80% would hand out educational information to their patients to enhance patient adherence to osteoporosis therapy. Most (76%) were willing to recommend a patient adherence programme to their patients, and 64% of physicians believed that other osteoporotic patients are a credible source of information for their patients. Physicians assessed the credibility of most of osteoporosis information sources significantly higher than patients did, including patient support group/programmes, websites, nurse specialists and books.

Table 3 Credibility of information sources, % of patients and physicians answering “yes” to statements that they believe are most credible for getting osteoporosis information; * $p < 0.05$

Information Source	Patients (%)	Physicians (%)	Gap (from patients' perspective)
Patient support group/programme	49	76	-27*
Websites	34	59	-25*
Nurse (UK: nurse specialist)	53	68	-15*
Books	52	65	-14*
Brochures from osteoporosis organisations	76	88	-12*
Radio programmes	38	47	-9*
Public places with information booths (shopping malls, etc.)	21	29	-7*
Other osteoporotic patients	58	64	-6*
General Practitioner	88	95	-6*
Specialist	94	99	-5*
Friends, family and colleagues	48	44	4
Pharmacy/health magazines	70	73	-3
Newspapers	37	40	-3
Pharmacist	73	76	-3
Women's magazines	40	37	3
TV health programmes	57	56	1

Discussion

The surveyed patients believed that they were better informed about their osteoporosis than the data revealed. More than two thirds felt very knowledgeable about their disease and the majority described the disease as a condition that “causes bones to be brittle and fracture/break easily”. However, over half of the surveyed patients incorrectly described osteoporosis as “just a part of getting old”. Other studies have reported data about the lack of patient knowledge in osteoporosis. Women ($n=437$) from rural Washington and Oregon underestimated their risk of osteoporosis, lacked basic knowledge about the prevention of osteoporosis and did less exercise than that recommended [12]. A low perception of osteoporosis and the uptake of screening services were reported in a study with Belgian women working in a university hospital in Brussels. Three times more of these women had undergone a mammography than a bone mineral density test [13].

Of the patients surveyed here, one in three could not identify any risk factors for osteoporosis. This highlights a lack of disease understanding, which needs to be addressed. In a study that looked at the knowledge and risk perceptions about osteoporosis and its treatment in older US women, it was reported that the health impact of osteoporosis was undervalued [14]. Women considered the disease to be controllable, not dreaded (considering other possible diseases) or life threatening. There was also confusion between arthritis and osteoporosis in a third of older women in a diagnosed and general sample. Scores were highest for the women on knowledge questions related to items that they could control, such as diet and exercise, and women who understood how their behaviour would affect osteoporosis were likely to act on that knowledge [14].

This survey found that patients fear fractures, yet their adherence to treatment is poor. Patients reported that they stopped taking their osteoporosis treatment for about 5.5 months on average, and approximately, a third of patients did not see a problem in missing a dose once in a while. Although they admitted to receiving information on the importance of taking their osteoporosis medicine, they did not fully understand that adherence significantly reduces fracture risk. Other studies of non-adherence include a national UK survey for women ($n=533$) over the age of 50 with osteoporosis who were taking or had taken bisphosphonate therapy within the previous 12 months [15]. Self-reported non-adherence to bisphosphonates (daily and weekly) was found to be independent of non-persistence (the decision to stop taking treatment). In this study, the reasons patients reported that they did not take medication included too many side effects (25%), wanting to switch to an alternative (20%) or that the medication was not helping

(12%). The side effects and other factors associated with non-persistence were thought to be modifiable in clinical practice through information, education and concordant partnerships [15].

The majority of physicians surveyed indicated that they proactively provided patients with information on the importance of treatment adherence and believed the average duration patients discontinued treatment to be 2.9 months. The gap of 2.6 months between the average duration of patients stopping osteoporosis treatment and the physician perceived time, and the wide disagreement in the desired features of osteoporosis treatment between the groups need to be addressed. Besides proactive information when treatment is first given, a source of supporting or supplemental information would help provide and reaffirm knowledge. Other studies have reported that the patient–health care provider relationship is a key factor that affects adherence [16]. In this study, focus groups were conducted in postmenopausal women ($n=37$) on at least one prescription or over-the-counter medication for osteoporosis. From these groups, it was reported that approximately 50% of women who took pharmacotherapy for osteoporosis discontinued within a year [16].

From the results of this survey, the impact of osteoporosis on patient quality of life is significantly underestimated by physicians. The quality of life questions were grouped into three general categories, activity and independence, emotional fear of fracture and employment status. In all of these categories, physicians believed patients to be less concerned than the patients actually reported. The gaps between patient and physician responses on quality of life were approximately 30% in this study, which represents a significant discrepancy that needs to be resolved.

In order to improve patient knowledge and adherence and address potential gaps in patient–physician perceptions, patient support tools were investigated. It was found that patients would like easy to understand tools and greater interaction with their physicians and other patients to help manage their osteoporosis. This need for patient support is an ongoing issue as shown by the results from a study conducted in the 1990s highlighting that both education and screening motivated lifestyle changes and are central to osteoporosis prevention [17]. White women ($n=771$) aged 30 years and over without a diagnosis of osteopenia or osteoporosis responded to a questionnaire about an osteoporosis educational programme. Only 16% of participants reported that their doctors had discussed osteoporosis with them [17]. Patient support is still a current issue for osteoporosis. In a 2006 clinical review on osteoporosis and its management, it was stated that compliance and persistence with treatments need to be improved and this can be achieved by better patient education and evaluating dosing regimens [18].

The most credible sources of information on osteoporosis for patients surveyed here were specialists, GPs and brochures from osteoporosis organisations. Patients want this information more frequently and in terms they can understand. This is in agreement with a study of women in the USA, which concluded that health care providers were the preferred source of information about osteoporosis [12]. However, a recent study [19] reported that passive patient education with printed information alone does not appear to be very effective. Indeed, the difference in adherence at 12 months between the treatment group and the control group was not significant when an educational osteoporosis leaflet alone was used. The use of patient reminder programmes and nurse monitoring has also been reported as beneficial [19], and another study investigating the perceptions and beliefs surrounding future fracture risk in osteoporotic patients concludes that messages about fracture risk would be better emphasised by well-designed written materials with attention grabbing graphics and as part of a nationwide post-fracture care initiative [20]. Patients in our survey also reported that talking to their friends about osteoporosis was beneficial and that they would value interaction with other people in their community to discuss day-to-day challenges of living with osteoporosis.

Surveyed physicians support patient programmes and are eager for tools that will help them better educate their patients about osteoporosis. Eight out of ten physicians in this survey would hand out educational information to their patients with approximately nine out of ten believing that brochures from osteoporosis organisations are one of the most credible sources for osteoporosis information. Physicians gave significantly more credibility to patient support groups, programmes and websites as information sources on osteoporosis than patients did. A dedicated website could provide a useful resource for osteoporotic patients, and a study looking at the idea of web-based care for certain components of osteoporosis management and education found that middle-aged women were receptive to the concept [21].

Like any survey, those who chose to respond (approximately 19% to 24% of patients and 32% to 49% of physicians) could hold systematically different experiences and therefore beliefs than those who did not. The low proportion of patients and physicians that chose to participate brings a certain bias that attenuates the conclusions of this survey and should be considered when assessing the results. Also poor memory or misunderstanding of the questions can contribute to inaccuracies in the data. Despite these limitations, there are clear disparities in patient and physician perceptions of osteoporosis, which indicate a need for increased patient support.

Conclusions

Results from this multinational survey show that patients are not as well informed as they believe and worry about their quality of life, but do not always adhere to treatment. The link between fracture prevention and treatment adherence is not fully understood by patients as they fear fractures but discontinue or miss doses of their treatment. Physicians underestimate their patients' concerns about quality of life, but are willing to endorse programmes encouraging better communication/education on managing osteoporosis. Initiation of a community-wide programme may enable patients to manage their concerns and address unmet needs in the management of osteoporosis. The programme should be:

- Easy to understand
- Improve patient–physician dialogue
- Allow patient–patient contact
- Encourage treatment adherence/persistence
- Help patients to maintain or improve their quality of life

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