Osteoporosis care through an Integrated, People-Centred Health Services framework lens: a hybrid qualitative analysis of international patient experiences

Caroline Verdonck, Ruben Willems, Borgermans Liesbeth

ABSTRACT

Objectives Globally, patients with osteoporosis have unmet needs in terms of care accessibility, patient-centredness and care comprehensiveness. The WHO developed the Integrated, People-Centred Health Services (IPCHS) framework to reorient and integrate healthcare systems using 5 interdependent strategies and 20 substrategies. Patients’ perspectives with regard to these strategies are poorly understood. We sought to relate patient-experienced gaps in osteoporosis care to the IPCHS strategies and identify key strategies to guide osteoporosis care reforms.

Design, setting and participants Qualitative online study of the experiences of international patients with osteoporosis.

Procedure Two researchers conducted semi-structured interviews in English, Dutch, Spanish and French that were recorded and transcribed verbatim. Patients were categorised according to their countries’ healthcare systems (universal, public/private and private) and fracture status. A hybrid (sequential theory-driven and data-driven) analysis was performed, with the IPCHS framework used for the theory-driven analysis.

Results Thirty-five patients (33 women) from 14 countries participated. Twenty-two patients had universal healthcare and 18 had experienced fragility fractures. Prioritised substrategies overlapped among healthcare systems, with reported shortcomings related primarily to ‘empowering and engaging individuals and families’ and ‘coordinating care’ (at varying levels). Patients with all healthcare types prioritised ‘reorienting care’, with different substrategies prioritised. Patients with private healthcare called for ‘improving funding and reforming payment systems’. Substrategy prioritisation did not differ between those receiving primary and secondary fracture prevention.

Conclusion Patients’ experiences with osteoporosis care are universal. Given the current care gaps and associated patient burdens, policymakers should make osteoporosis a(n) (international) health priority. Integrated osteoporosis care reforms should focus on patient-reported experiences with and be guided by priorities in IPCHS strategies, taking into account the healthcare system context.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ Contacting global and national patient (advocacy) organisations enabled us to capture a global patient perspective on osteoporosis care.
⇒ The hybrid qualitative analysis using the Integrated, People-Centred Health Services framework provided a deeper understanding of needed foci in future osteoporosis care reforms.
⇒ The use of multiple languages in interviews allowed broad patient participation.
⇒ Contacting patients through patient (advocacy) organisation may have introduced inclusion bias.

INTRODUCTION

The alignment of healthcare systems to meet the challenge of caring for the world’s rapidly growing older population is among the most important goals of the WHO’s Decade of Healthy Ageing (2021–2030) platform. This effort entails ensuring the availability of high-quality healthcare services for diseases disproportionately impacting ageing individuals, such as osteoporosis. Osteoporosis is a chronic, metabolic skeletal disease characterised by reduced bone mineral density (BMD) and micro-architectural alterations that predispose individuals to fragility fractures. More than 200 million people have osteoporosis, and 33% and 20% of affected women and men, respectively, aged ≥50 years, experience one or more fractures. The prevalence of osteoporosis is expected to increase exponentially in the next decades as the population ages.

Large gaps in osteoporosis care provision exist, and a downward trend in pharmacological treatment has been observed in the last decade in Europe and the UK. Cost-effective diagnostic, preventive and therapeutic strategies for fragility fractures are available, but
a substantial proportion of patients with osteoporosis do not receive treatment. Among those receiving treatment, adherence rates are low.15 This care gap places substantial burdens on patients and society, but may be addressed by the offering of high-quality osteoporosis care services. High-quality healthcare services increase the likelihood of desired health outcomes for individuals and populations. For osteoporosis, services that are patient centred, and thus responsive to patients’ individual preferences, values and needs, are needed to prevent fragility fractures.

The WHO has developed the Integrated, People-Centred Health Services (IPCHS) framework to support the reorientation of healthcare services toward more integrated and thus high-quality care provision. This framework aims to support care integration by engaging in five interdependent strategies:

- Empowering and engaging people and communities,
- Strengthening governance and accountability,
- Reorienting the model of care,
- Coordinating services within and across sectors, and
- Creating an enabling environment.

Each of these strategies is further divided into substrategies (figure 1) for which non-exhaustive lists of potential policy interventions are provided. The WHO argues that the adoption of a larger number of substrategies is more likely to yield improvements and cautions that a lack of progress in one area may undermine progress in others.19

The case of fracture liaison services (FLS) provides an example of successful IPCHS strategy implementation to improve care quality while confining costs.6 20 FLS are coordinator-based multidisciplinary models of secondary fracture prevention services,21 designed to identify patients who are at increased risk of fracture, provide a comprehensive assessment and initiate treatment.22 They are considered the gold standard for integrated osteoporosis care (IOC). The Capture the Fracture programme developed by the International Osteoporosis Foundation has pushed reorientation toward IOC, with 791 FLS currently operating in 51 countries.21 However, universal access to FLS remains below par, and patients’ experiences with osteoporosis care (in FLS and non-FLS settings) are not well integrated into such care’s development and implementation. As an understanding of patients’ experiences is key to the tailoring of services to their preferences, values and needs, this study was conducted to (1) identify patient-perceived gaps in osteoporosis care, (2) relate these gaps to IPCHS strategies and (3) identify key IPCHS strategies to guide osteoporosis care reform.

**METHODS**

**Methods**

This study was a global online interview-based qualitative study. Participants were invited via osteoporosis and bone health patient advocacy organisations, which were sought online in the six WHO regions (Africa, the Americas, the Eastern Mediterranean, South-East Asia and the Western Pacific).22 The aim was to include at least two patients from two WHO countries per region. An email that outlined the study and requested assistance with patient recruitment was sent to the organisations. The opportunity for
a virtual meeting was offered in case any organisation representative had questions prior to participation. Non-responding organisations received two reminders, after which no further contact was sought. Organisations that agreed to participate were asked to invite patients to participate by posting an announcement on their web pages and/or other normally used patient communication media. The announcement provided information about the study and a researcher’s contact details that patients could use to volunteer.

**Participants**
Volunteering patients were assessed for eligibility. Patient eligibility criteria were: (1) age ≥18 years; (2) diagnosis of osteoporosis; (3) provision of written informed consent to study participation prior to being interviewed; and (4) ability to speak English, Dutch, French or Spanish.

Eligible volunteers received written information about the study and an informed consent form. After each consent form had been signed and returned, a virtual meeting was planned via email.

**Interviews**
Two interviewers (CV and BL) conducted in-depth semi-structured online interviews with the participants in Dutch, French, English or Spanish using Microsoft Teams (V4.2.4.0) or Zoom online conferences between November 2021 and July 2022. CV is a medical doctor and works as a healthcare organisation researcher, and BL is a lecturer on integrated care at Ghent University. The interview guide developed for this study (online supplemental appendix 1) focused on five aspects of the experiences of patients with osteoporosis: (1) societal awareness of the disease and support of affected patients, (2) identification of patients at high risk for fragility fractures, (3) diagnosis and evaluation of such patients, (4) treatment initiation and (5) follow-up and comprehensive re-evaluation. All interviews were recorded and transcribed verbatim in the original language. Interviews were held until no new themes emerged.

**Data analysis**
For analysis, the patients were categorised based on (1) the self-reported occurrence of one or more fractures and (2) the healthcare systems in their countries of residence. The latter was classified as universal healthcare (government-guaranteed coverage for all citizens), public/private healthcare (universal coverage and ≥33.33% domestic private health expenditure relative to the total health expenditure, according to the WHO’s Global Observatory) and private healthcare (no universal coverage).

A hybrid qualitative analysis of the untranslated interview transcripts, driven sequentially by the theory and data performed in English. In the theory-driven analysis, two researchers (CV and BL) independently linked patient experiences to IPCHS substrategies and identified key substrategies that patients indicated needed to be prioritised in osteoporosis care reform. One researcher (CV) performed the data-driven analysis for each IPCHS substrategy to identify key substrategies and gain insight into patients’ experiences with and recommendations for them. The analyses were performed using NVivo V12 for Windows. Quotations extracted for the reporting of results were forward–backward translated into English by CV and RW.

All methods were in accordance with the Declaration of Helsinki. All participants provided written informed consent (online supplemental appendix 2) after receiving information about the study and prior to participation.

**Patient and public involvement**
This study was conducted to characterise patients’ experiences with different aspects of osteoporosis care. The interview guide (online supplemental appendix 1) was structured according to the healthcare journeys of such patients. A scoping review of the literature was performed to identify gaps in knowledge on patients’ perspectives on osteoporosis care, and interview questions about patients’ lived experiences and/or expectations were developed based on its results. In a pilot test, four patients assessed the clarity, comprehensiveness and relevance of the preliminary interview guide. The guide was adapted according to these patients’ suggestions. Thus, although we did not directly involve patients or the public in interview guide development, we did so indirectly through the review and pilot testing. Moreover, the semi-structured interview format allowed interviewees to ask questions or make observations that departed from the guide’s topics.

**RESULTS**

**Participant characteristics**
Thirty-five patients (33 women) residing in 14 countries participated in the study (table 1). The mean interview duration was 45.38 min (range: 10.78–82.61 min). Most patients resided in countries with universal healthcare. Eighteen patients had experienced one or more fragility fractures. Mean age was 66 years (range: 38–88 years).

**Links between patient experiences and IPCHS substrategies**
Regardless of healthcare system type, patients elaborated mainly on themes related to the ‘empowering and engaging individuals and families’ IPCHS substrategy and the ‘reorienting the model of care’ and ‘coordinating care’ strategies, although the prioritisation of substrategies within these two strategies varied. Patients living in countries with universal and public/private healthcare focused on care coordination at the individual level, whereas those living in the USA (private healthcare) focused on this strategy at the sectorial level. The latter were also the only patients to speak extensively on ‘improving funding and reforming payment systems’, which was touched on only lightly by others. For the ‘reorienting the model of care’ strategy, the interviewees prioritised three (of five) substrategies: ‘defining service priorities over the life course needs’, ‘revaluing promotion, prevention and public health’ and ‘building strong primary care-based systems’.

Table 1  Patient characteristics

<table>
<thead>
<tr>
<th>Age (years)</th>
<th>Gender</th>
<th>Country</th>
<th>Healthcare system</th>
<th>Previous fragility fracture(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>68</td>
<td>Female</td>
<td>Argentina</td>
<td>Public/private</td>
<td>No</td>
</tr>
<tr>
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<td>Public/private</td>
<td>No</td>
</tr>
<tr>
<td>70</td>
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<td>Universal</td>
<td>No</td>
</tr>
<tr>
<td>54</td>
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<td>Universal</td>
<td>Yes</td>
</tr>
<tr>
<td>64</td>
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<td>Yes</td>
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<td>Universal</td>
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<tr>
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<td>Private</td>
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<tr>
<td>63</td>
<td>Female</td>
<td>USA</td>
<td>Private</td>
<td>No</td>
</tr>
</tbody>
</table>

UK, United Kingdom; USA, United States of America.

This prioritisation relative to other substrategies differed according to the healthcare system (figure 2). Overall, IPCHS (sub)strategy prioritisation did not differ between those with and without previous fragility fractures.

Patients’ experiences with the operationalisation of the main IPCHS substrategies

Although the three groups’ prioritisation of substrategies overlapped, patients’ experiences with the operationalisation of these substrategies differed. Descriptions of approaches to the implementation of the substrategies that the interviewees considered to be important are provided in table 2.

Empowering and engaging individuals and families

Patients with universal health coverage (with or without high private payments) suggested that timely and comprehensive patient education about osteoporosis was lacking: ‘At the time of diagnosis, someone should have taken the time to explain what osteoporosis was’ (Patient 15). They felt that this lack hindered self-management—‘Doctors assume you are born with the knowledge to take care of yourself’ (Patient 12)—for which support is ‘close to non-existent’ (Patient 10). Patients feel belittled—‘I had lower back pain for years! But they [physicians] just shrugged their shoulders!’ (Patient 12)—and did not have therapeutic alliances with caregivers: ‘It was a very paternalistic approach’ (Patient 9). They indicated that they needed a greater understanding of the physiological and psychological consequences of osteoporosis: ‘It would be ideal if you had a good primary care physician (PCP) who integrates what is necessary for each individual patient’ (Patient 25). This perceived knowledge gap, accompanied by suboptimal shared decision-making, contrasted with patients’ desire to take responsibility for their health: ‘I want to be involved and engaged in my treatment’ (Patient 10).

Patients with private healthcare predominantly expressed discontentment with the lack of a holistic approach—they never looked at my lifestyle, all the things that I do to maintain my health. They just focus on this T-score’ (Patient 30)—and strong therapeutic relationships: ‘My endocrinologist is a fellow, and my PCP a resident. They’re both leaving, so again it will be new people to get used to’ (Patient 31).

Coordinating care for individuals

Patients with universal health coverage (with and without substantial private payments) experienced siloed care fragmentation, as ‘there’s no link between the things that could be offered to help patients’ (Patient 15). They perceived a lack of coordination—‘That’s my story: a lot of coincidence and personal initiative’ (Patient 21)—and expressed the need for ‘more continuous, tailored and personalised care’ (Patient 1) delivered by a multidisciplinary team: ‘One shouldn’t just get a doctor to treat osteoporosis. It would be ideal if you could receive advice from a nutritionist, counselling for physiotherapy…,’ (Patient 25). Patients brought up the idea of specialised clinics: ‘You know what is lacking? A centre. That is accessible to people’. (Patient 14).

Patients using private healthcare confirmed the lack of coordination. They mentioned that they had to develop their own health plans—‘I have come up with my whole programme. There’s no one to help you’ (Patient 32) and plead for care pathways: ‘I wish they had this whole protocol’ (Patient 32).
Coordinating across sectors

Patients with private healthcare perceived that the multifactorial origin of osteoporosis was not appreciated and that current ‘modern’ physicians ‘are very quick to fix things with medication’ (Patient 30). They did not feel acknowledged and had turned to alternative treatments: ‘I do acupuncture. It is very helpful!’ (Patient 31). This perception was shared by patients in all healthcare settings, who felt that their systems fail patients who are not open to pharmacological treatment: ‘For a lot of doctors, when you don’t want pharmacological treatment, there’s no need for you to see them’ (Patient 25). Patients recommended (1) more research into non-pharmacological therapies—‘Are there any other intervention types under research that may be helpful?’ (Patient 25), (2) faster permeation of research insights into practice—‘What I found shocking was this gap of 18 years between this [Women’s Health Initiative] study and now. The information wasn’t unknown.’ (Patient 14) and (3) ‘improving information for physicians’ (Patient 15).

Table 2  Approaches to the implementation of the identified IPCHS strategies

<table>
<thead>
<tr>
<th>Sub-strategy</th>
<th>Strategic approach</th>
</tr>
</thead>
<tbody>
<tr>
<td>Empowering and engaging individuals and families</td>
<td>Enabling patients and their families to take responsibility for their own care by providing education, building therapeutic alliances, being involved in the decision-making process and receiving self-management support.</td>
</tr>
<tr>
<td>Coordinating care for individuals</td>
<td>A range of strategies that help to achieve more continuity of care and enhance patient experiences through focusing on improved coordination during care transitions.</td>
</tr>
<tr>
<td>Coordinating across sectors</td>
<td>Collaboration between multiple stakeholders within and beyond the healthcare sector. It implies strong leadership in intersectoral collaborations in order to respond to healthcare (sector) needs.</td>
</tr>
<tr>
<td>Building strong primary care-based systems</td>
<td>Reaching the entire population and guaranteeing universal access to services. This requires a.o. adequate funding, appropriate training and strong connections with other (health) services.</td>
</tr>
<tr>
<td>Revaluing promotion, prevention and public health</td>
<td>Health services that contribute to the delivery of essential public health functions such as promotion, prevention and public health. It entails these services are delivered within a defined public area.</td>
</tr>
<tr>
<td>Defining services over the life course needs</td>
<td>The package of health services offered at different levels of the care delivery system and based on the best available evidence, covering the entire life course.</td>
</tr>
<tr>
<td>Improving funding and reforming payment systems</td>
<td>Aspects related to adequate funding and financial incentives that limit undue out-of-pocket expenses while providing high-quality care services.</td>
</tr>
</tbody>
</table>

Text in this table was extracted from the WHO’s IPCHS framework.19 a.o., amongst others; IPCHS, Integrated, People-Centred Health Services.
Building strong primary care-based systems

Interviewees living in countries with universal health coverage recognised the role of primary care services as gatekeepers to specialised care: ‘I went to my PCP and he sent me to the right specialist’ (Patient 22). In contrast, those with private healthcare accessed secondary care without PCP consultation (reflecting the lack of a gatekeeping function), seeking (inappropriate) care until they got what they desired: ‘I finally found an endocrinologist who was willing to prescribe bone markers. All the doctors said they were unreliable. But that doesn’t matter! I just need them for myself!’ (Patient 30).

Patients with universal coverage recognised the potential of well-integrated primary care services—‘I go to a community health centre, which is a wonderful model’ (Patient 9)—in providing multidisciplinary care: ‘I can see a physiotherapist, or an occupational therapist...’ (Patient 10). They felt that it was important that ‘someone is in charge’ (Patient 7)—‘I want to consult someone who sees me as a whole’ (Patient 2)—but their perspectives on who that physician should be varied. Some interviewees preferred super-specialists, whereas others valued their PCPs more: ‘I think my PCP has an important role to play in my care’ (Patient 3).

Revaluing promotion, prevention and public health

Patients residing in countries with high private payments or without universal healthcare commented on the limited awareness of osteoporosis and its consequences at the professional level—‘There’s no clinician thinking of checking you’ (Patient 31)—among the lay public—‘If only osteoporosis was made known to the people’ (Patient 17)—and among policymakers: ‘There’s considerably less knowledge or awareness [of osteoporosis] among policymakers compared to diabetes or cancer’ (Patient 25). Patients also perceived a limited emphasis on prevention: ‘The only thing they say is “take enough calcium”’ (Patient 25). Although osteoporosis screening is offered routinely in some countries—‘Women get an annual check-up for cervical cancer, breast cancer and osteoporosis’ (Patient 2)—patients felt that bone health promotion was offered too late in life: ‘When you’re at the age of DXA screening, you’re already down the road to hell’ (Patient 29). They desired early bone health awareness efforts: ‘Tell people about osteoporosis. That’s a priority! I just need them for myself!’ (Patient 31).

Defining service priorities over the life course needs

Patients with public/private healthcare systems reported substantial differences in care quality: ‘It really depends on the gynaecologist, whether you get bone densitometry during menopausal transition or not’ (Patient 1). They suggested a more holistic life-course approach in which services are offered on the occurrence of distinct life events: ‘Perhaps women who reach menopause might be offered BMD testing’ (Patient 25).

Improving funding and reforming payment systems

Patients with private health coverage expressed concern about the affordability of pharmacological and non-pharmacological treatments—‘The medication is expensive. We have several college students in the house and it doesn’t feel comfortable to allocate the money to treatment’ (Patient 32) as ‘it’s all out-of-pocket’ (Patient 31). Patients with universal coverage did not prioritise such concerns, but noted several obstacles related to healthcare funding: ‘healthcare is very underfunded’ (Patient 13) and ‘there aren’t enough doctors’ (Patient 11). They expressed that ‘much more investment in healthcare’ (Patient 13) was needed to reorient the system, as resources for timely care were insufficient: ‘You have to wait 6 months for an investigation’ (Patient 12). These patients identified financial barriers to early BMD testing—‘Only if the DXA demonstrated osteoporosis could I have it reimbursed’ (Patient 15)—and non-pharmacological prevention and treatment: ‘It would be nice to have my physiotherapy reimbursed’ (Patient 20). Those in combined systems described important quality differences between the public and private sectors due to underfunding: ‘There’s a difference between a hospital and a healthcare centre. Those who earn less, go to the hospital’ (Patient 1).

DISCUSSION

This qualitative study was conducted to summarise patients’ experiences with contemporary osteoporosis care, with the WHO’s IPCHS framework used to identify key areas for improvement. The theory-driven analysis revealed prioritisation across all healthcare systems of the ‘empowering and engaging individuals and families’ sub-strategy and no difference in the experiences of patients with and without previous fragility fractures, likely because the main identified sub-strategies cover aspects of care relating to primary and secondary fracture prevention. The prioritisation of other sub-strategies differed among healthcare systems, reflecting the importance of the osteoporosis care context, but also showed substantial overlap, enabling the identification of sub-strategies requiring attention. Patients with universal and public/private healthcare prioritised ‘coordinating care for individuals’, whereas those with (substantially) private healthcare prioritised ‘revaluing promotion, prevention and public health’. Patients with private and universal healthcare, but not those with public/private systems, prioritised ‘building strong primary care-based systems’. Although patients with all healthcare types mentioned ‘improving funding and reforming payment systems’, only those with private healthcare prioritised this sub-strategy. The data-driven analysis revealed little perceived patient-centredness across healthcare sectors in terms of patient education, shared decision-making and therapeutic alliances (‘empowering and engaging individuals and families’). The latter is an important aspect of care tailoring with respect to the capacity of patients...
with multimorbidity to follow treatment recommendations. It requires the training of patients and health professionals, for whom the incorporation of patient counselling into consultations remains a challenge. Shared decision-making results in increased patient satisfaction, improved functional status, optimised self-management and better treatment adherence, but it requires comprehensive information about osteoporosis, therapeutic options and possible side effects. This information need has been reported, but its persistence is surprising, as two-thirds of this substrategy’s interventions have been operationalised in IOC. Furthermore, the effectiveness of different education programmes has been demonstrated.

Patients navigating the US’s private healthcare system felt better informed, but expressed discontentment that their knowledge was not taken into account, which hindered strong therapeutic alliance building. The osteoporosis care gap could be addressed in a patient-centred manner using a participatory approach, with patient empowerment while recognising the need for healthcare providers’ expertise and aptitude in facilitating patient self-management.

The need for more care coordination expressed by patients with (partial) universal coverage reflects the frequent lack of standardised follow-up and failure to care for patients seeking non-pharmacological treatment (‘coordinating across sectors’). The multi-aetiological nature of osteoporosis necessitates a multidisciplinary approach, and non-pharmacological interventions provided by non-physicians can reduce the fall risk in patients at risk of (re-)fracture. As did our interviewees, patients in Hawarden et al.’s study recommended a multidisciplinary care pathway for osteoporosis.

Multidisciplinary care pathways, such as FLSs, have been proven to cost-effectively reduce fracture rates. Such pathways should be tailored to individuals’ needs based on predefined referral criteria and require a single physician overview. Debate on whose responsibility this is persists, but PCPs have the opportunity and responsibility to assume this role. This approach aligns with the request for ‘building strong primary care-based services’ of patients with (partial) universal health coverage. An example of effective primary care-based services is the primary care fracture clinic in Queensland, Australia, where collaboration between hospital and primary care has improved patient experiences and service provision efficacy without compromising health outcomes. Considering the low cost of osteoporosis treatment relative to that of fracture treatment, a stronger primary care system may prevent overuse and misuse and reduce costs. Strong primary care-based systems may also be able to provide more regular follow-up, which effectively improves patient compliance and persistence with therapy. However, the number of primary care pathways for osteoporosis management remains limited.

Service priorities over the life course needs. Currently, bone health is often brought up only with older patients or after fracture occurrence (if at all). This approach ignores the accrual of fracture risk throughout the life course and reflects the lack of awareness at public, clinical and policy levels, which results in limited bone health promotion (‘Revaluing promotion, prevention and public health’) relative to preventive efforts for other diseases. Mass media campaigns succeeded in reducing risk behaviours for cardiovascular disease and may also be valuable in reducing falls and fragility fractures. Our interviewees mentioned the need for information provision at younger ages and appropriately timed (ie, at menopause) screening. Ideally, a life-course approach begins in utero: a 1 kg increase in birth weight is associated with a 1.49 g increase in bone mineral content. Pregnant women should be made aware of bone health and supported in addressing their fetus’s needs, with an emphasis on achieving and maintaining the genetic potential peak bone mass. Later in life, systematic efforts to identify patients at high risk (ie, with non-modifiable factors) of fragility fracture should be made. Two-step osteoporosis screening, with Fracture Risk Assessment Tool administration before further investigations, has been recommended.

A coordinated, multidisciplinary life-course approach requires broader coverage that reduces treatment barriers (‘improving funding and reforming payment systems’). A microsimulation study based on US Medicare data suggested that the 20% increased use of and improved reimbursement for dual-energy X-ray absorptiometry examinations and the doubling of osteoporosis treatment rates would still be cost-saving. Other research has demonstrated that national health coverage is cost-effective, improves population health and increases economic development. Universal health coverage could also reduce social differences in care accessibility. Many patients relying on public services reported that long waits for diagnostic procedures and the lack of PCPs limited fracture prevention service accessibility. Especially in remote areas, telemedicine may be a viable solution, but overall healthcare funding should be adequate.

Strengths and limitations
Despite presenting a unique patient perspective, this study has some limitations. First, patients were recruited via patient (advocacy) associations and interviews were held online, which may have resulted in a biased group of affiliated patients. Second, only two men participated in the study, which is under-representation as 25% of patients with osteoporosis are men. Third, mainly private healthcare was represented only by the USA, which may have biased the reported experiences in this setting. Fourth, language barriers may have imposed participation bias toward highly educated patients. However, we conducted interviews in English, Spanish, Dutch and French, the first or second languages in many countries. Furthermore, patients were asked not only about their
personal experiences, but also about the overall accessibility to osteoporosis care for all social classes in their countries, with additional information on health policies and reimbursement strategies elucidated when necessary. Fifth, patients may have given socially acceptable answers due to loyalty to their physicians. We sought to address this potential bias by repeatedly reassuring patients that our study would have no impact on their relationships with their healthcare providers. Sixth, we did not meet our objective to include at least two patients from two countries per WHO region, but the interviews revealed smaller between-country than between-person differences in experiences, supporting our finding that no standardised, comprehensive service package is available for patients with osteoporosis.

Our study has several strengths. It qualitatively captures international patient perspectives on osteoporosis care. Previous research has focused on patients’ lived experiences with osteoporosis, experiences with specific programmes and attitudes toward treatment, or has been quantitative. We provide a comprehensive overview of the osteoporosis care journey, ranging from the first event (diagnosis or fracture) to long-term care and consequences, with unique insights into how care gaps affect patients over time. Furthermore, we related patient experiences to the internationally recognised IPCHS framework, on which stakeholders can build to reorient osteoporosis care. Finally, our approach advocates attention to patients’ voices, furthering the integration of osteoporosis care.

Conclusion
Patients’ experiences with osteoporosis care are universal. Given the current care gaps and associated patient burdens, policymakers should make osteoporosis a(n) international national health priority. IOC reforms should focus on patient-reported experiences with and be guided by priorities in IPCHS strategies, taking into account the healthcare system context.

Contributors CV is the responsible author for the overall content and accepts full responsibility for the work and/or the conduct of the study, had access to the data, and controlled the decision to publish. Interview guide development: RW and LB. Patient organisation outreach: CV and LB. Patient communication: CV. Interviews and analysis: CV and LB. Writing: CV. Rewriting and editing: CV, RW and LB. Figures and table production: CV.

Funding This study was made possible by a value-based partnership between Ghent University and Amgen. This partnership had no impact on the study design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Consent obtained directly from patient(s).

Ethics approval The Ghent University Hospital Ethics Committee approved this study (BC-10951). All procedures were in accordance with the Declaration of Helsinki. All participants voluntarily signed an informed consent form after receiving written information about the study and before participation.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon reasonable request. Transcripts of the patient interviews are available at: doi: 10.17605/OSF.IO/AZ6E8.

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Interview guide
‘Patients’ perspectives and expectations in osteoporosis care’

Caroline Verdonck, MD
Ruben Willems, PhD
prof. Liesbeth Borgermans, PhD
1. **Guidelines for the interviewer**

Before the start of the interview:

✓ Make sure the informed consent form is signed.
✓ Assure confidentiality
✓ Clearly state to the patient that there are no wrong answers

2. **Interview questions**

**SCREENING**
1. When and why were you screened for osteoporosis?
2. What did you expect at the moment of referral for (DXA) screening?
3. With your information, what could have been done differently to get the diagnosis earlier?
4. More in general, if you had the keys in your hand, in what situations would you screen for osteoporosis in society?

**DIAGNOSIS**
1. In what setting and by whom did you receive your diagnosis of osteoporosis?
2. Could you think of another way or another setting or person that would have been a better option to receive your diagnosis?
3. What did it mean for you to hear the diagnosis of osteoporosis?
4. In what way did you expect osteoporosis would have an impact on your life?
5. Did you have the feeling that you were prepared to receive the diagnosis of osteoporosis?
6. What would have helped you to cope better with the diagnosis at the time you received it?

**INFORMATION EXCHANGE**
1. Which kind of information did you expect to receive?
2. Who do you expect to provide you with such information?
3. How would you like to receive such information?
4. When in the patient journey is the right time to receive such information?
5. Is there any other information you would have liked to receive? Please elaborate on which information, from who, how and when you would like to receive this.
6. Was osteoporosis merely presented as a risk factor or a disease?
7. In what way would that make a difference for you?

**DELIBERATION**
1. Are there any (other) treatment that you did expect to discuss? And with whom?
2. What would help you to ensure the continuation with your osteoporosis treatment?
3. A problem often encountered in osteoporosis care is the discontinuation of medical treatment. What could be reasons for you to discontinue your medication?

**DECISION MAKING**
1. To understand your patient journey in full, which treatment advice did you receive and which decisions have been taken?
2. Who should take the ultimate decision regarding which treatment should be started up?
3. Which treatment decisions do you prefer to take yourself?
4. Which treatment decisions do you prefer the healthcare professional takes for you?

**FOLLOW-UP PART A**

*For patients who have received one or more follow-up visits with a healthcare professional already. In case you have not received a follow-up visit yet, please proceed to “FOLLOW-UP PART B”*

1. How did your follow-up visit go?
2. Did you have any expectations about the follow-up visit? Which were they?
3. Which expectations were fulfilled and which not?
4. Did you expect to undergo testing? If yes, please elaborate on which tests, why these are important to you and which explanation you received about them.
5. Did you expect to receive a medication review? If yes, please elaborate on why this is important to you and whether this happened or not.
6. Did you expect to discuss lifestyle? If yes, please elaborate on why this is important to you and whether this happened or not.
7. What are the most important issues for you that you would like to have discussed during a follow-up visit?
8. In an ideal situation, which healthcare professional is best fit to discuss these important issues with you?
9. How often would you like to have a follow-up consult and why?

**FOLLOW-UP PART B**

*For patients who have not yet received follow-up visits with a healthcare professional already. In case you have already received a follow-up visit yet, please proceed to “STAKEHOLDERS”*

1. What do you expect from a follow-up moment?
2. What are the most important issues for you that you would like to have discussed during a follow-up visit?
3. Do you expect to undergo testing? If yes, please elaborate on which tests, why these are important to you and which explanation you would like to receive about them.
4. Do you expect to receive a medication review? If yes, please elaborate on why this is important to you.
5. Do you expect to discuss lifestyle? If yes, please elaborate on why this is important to you?
6. In an ideal situation, which healthcare professional is best fit to discuss these important issues with you?
7. How often would you like to have a follow-up consult and why?

**STAKEHOLDERS**

1. Who are the most important healthcare professionals in your patient journey? Please elaborate on why and what their roles are.
2. Did you seek more help next to regular care to manage your osteoporosis? If yes, please elaborate on which help and why.
3. How do you like to see yourself as a patient? Please elaborate on whether this matches reality.
4. Could you describe the necessary conditions for good self-management?
5. Can informal caregivers help you cope with osteoporosis? Please elaborate on how and which impact they have for you?
6. Have you thought about seeking support of peers? Please elaborate on what kind of support, why and whether you could find this or not.

**CONCLUDING QUESTIONS**
1. In general, how did osteoporosis impact your life?
2. If this was a perfect world, and you were able to improve care for patients with osteoporosis, which are the three most important things you would like to change.
3. Although we have tried to discuss the whole patient journey, there might still be other things you would like to mention. Please feel free to write these down here.

**THANK YOU FOR PARTICIPATING IN THIS STUDY!**
Participant information form:

Project:
QUALITATIVE RESEARCH ON PATIENTS’ PERSPECTIVES AND EXPECTATIONS IN OSTEOPOROSIS CARE

Study description and aim:

You are invited to participate in a study. Before you decide to participate in this study, take sufficient time to read this information sheet carefully and discuss this with the investigator or other people of your choice. Please take time to ask questions if there are any uncertainties or if you require additional information. This process is called "informed consent" for participation to a study. Once you have decided to participate in the study, you will be asked to sign the consent form at the end of this information sheet.

The Department of Public Health and Primary Care (Ghent University) has set up an international study in osteoporosis patients in which experiences with and expectations of osteoporosis care will be explored by means of this semi-structured interview. This research aims to analyze the experiences with and expectations of patients regarding the care they received for osteoporosis throughout the 6 WHO-regions. We kindly ask you to provide us with some of your time in order to perform the interview. The estimated duration will be approximately 60 minutes. The interview will be held online and will be recorded.

This study has been approved upon by the Ethics Committee from the University Hospital of Ghent and Ghent University (Belgium), and will be carried out in accordance with the guidelines for good clinical practice (ICP/GCP) and the Helsinki Declaration, formulated for the protection of participants of clinical studies. Data gathering will be executed under the supervision of Prof. Dr. Liesbeth Borgermans, associated to Ghent University.

Approval and refusal:
You are free to participate or not.
In case you decide not to participate, you are free to do so without providing the researchers or anyone else with a reason for refusal. This decision will have no consequences on your further relation with the researchers.
In case you agree to participate, we kindly ask you to sign the informed consent.

Benefits
This research will not provide you with any medical or other advantages, but the results may lead to new and/or more efficient methods to manage osteoporosis patients with osteoporosis.

Costs
Participation will not lead to additional expenses on your part and won’t result in any any financial benefits.

Confidentiality:

In accordance with the Belgian law of August 22, 2002, relating to the rights of the patient, the General Data Protection Regulation (or GDPR) (EU) 2016/679 of April 27, 2016 (that is in force since May 25, 2018) and the Belgian law of July 30 2018, on the protection of individuals related to the processing of personal data and on the free movement of such data your privacy will be respected and you will be able to access the data collected about you. Each error can be corrected at your request.
If you consent to participate in this study, we will process your data in accordance with the purpose of the clinical study. This processing of data is provided by law on the basis of Article 6, paragraph 1 (a) and Article 9, paragraph 2 (j) of the General Data Protection Regulation.

All information collected during this study will be pseudonymized. The key to the code assigned to you will only be accessible to the investigators or their appointed replacement. Only pseudonymized data will be used for analysis and in any type of documentation, reports or publications (in the medical scientific literature and/or at medical conferences) concerning this study. Therefore, confidentiality of the data will always be guaranteed. Both personal data and data concerning your health will be processed and stored for at least 20 years. The controller of the data is the institution of the principal investigator of the study, Prof. Liesbeth Borgermans (UGhent). Her research team will gain access to your personal file. In the context of data protection, the data will only be processed by personnel belonging to the research team and designated by and under the responsibility of the principal investigator, including internal employees with a non-healthcare profession.

If you wish, the Data Protection Officer can provide you with more information about the protection of your personal data. Please contact Hanne Elsen, privacy@ugent.be.

Representatives of the promoter, auditors, the Medical Ethics Committee and the competent authorities, all bound by professional secrecy, can have direct access to your medical records under the responsibility of the investigator (or one of his/her collaborators) in order to check the study procedures and/or the data, without violating its confidentiality. This is only possible within the limits of the relevant laws. By signing this consent form and having received the preliminary explanations, you consent to this access.

The Belgian supervisory Data Protection Authority responsible for enforcing data protection legislation can be reached via the following contact details:

Data Protection Authority (DPA)
Rue de la Presse 35 – 1000 Brussels
Tel: +32 2 274 48 00
E-mail: contact@apd-gba.be
Website: www.dataprotectionauthority.be

Insurance: 
Under the Experiments Act of 7 May 2004 we are obliged to insure participants of scientific research for their participation against any possible risk (however small). The probability of suffering any harm due to participation in this study is extremely low. However should this be the case, which is very rare, an insurance has been taken out in accordance with the Belgian law of 7 May 2004, covering this possibility.

For this purpose, insurance has been taken out with faultless liability in accordance with the Human Experiments Act of 7 May 2004 (Allianz Global Corporate & Specialty; Uitbreidingstraat 86, 2600 Berchem; Tel: +32 33 04 16 00; policy number for UZ Ghent BEL001889 – policy number for UGhent BEL000862).

Contact
If an injury occurs or if you would like to receive more information about this study or about your rights, you can contact the investigator or an employee of his/her team at any time during the course of the study:
Name: Caroline Verdonck
Address: C. Heymanslaan 10, 9000 Gent (Belgium)
Email address: caroline.verdonck@ugent.be
**Informed consent:**

I have read and understood the document “Information sheet for the participants” page 1 to page 3 and I have received a copy of this document. I have been informed about the nature of the study, its purpose, its duration and what is expected of me.

I understand that participation in the study is voluntary and that I can withdraw from the study at any time without giving a reason for this decision and without this having any influence on my further treatment.

I am aware that this study has been approved by an independent Medical Ethics Committee at UZ Ghent and Ghent University and that this study will be conducted according to the guidelines for good clinical practice (ICH/GCP) and the declaration of Helsinki, designed to protect people participating in experiments. This approval should under no circumstances be taken as an incentive to participate in this study.

I have been informed that both personal data and data concerning my health are processed and stored for at least 20 years. I am aware that I am entitled to access and correct this information. As this data is processed for medical-scientific purposes, I understand that access to my data may be postponed until after the end of the study. If I want access to my data, I will address the doctor-investigator who is responsible for the processing of the data.

*For the participant:*
I agree to participate in the following parts of the study:

- ☐ I agree to fully cooperate with the researchers
- ☐ I approve to having the online interview being recorded
- ☐ I approve to having my personal data being processed in a pseudonymized manner

Name researcher:    Name participant:

Date:       Date:

Signature      Signature

*(Two copies must be completed. The original is kept by the investigator in the hospital for a period of 20 years, the copy is given to the participant.)*

*For the researcher:*

- ☐ I declare that I have provided the necessary information regarding this study (the nature, the purpose, and the foreseeable effects) orally and a copy of the information document to the participant.
- ☐ I confirm that no pressure has been exerted on the participant to allow him/her to participate in the study and I am prepared to answer any additional questions.