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,
a substantial proportion of patients with osteoporosis do not receive treatment.10–14 Among those receiving treatment, adherence rates are low.15 This care gap places substantial burdens on patients16 and society,17 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,18 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.19 This framework aims to support care integration by engaging in five interdependent strategies:

1. Empowering and engaging people and communities
2. Strengthening governance and accountability
3. Reorienting the model of care
4. Coordinating services within and across sectors
5. 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.20 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 websites 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 untransliterated 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 V.12 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’ substrategies, 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’.

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 1).

Patients with private health care 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 are 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…’, ‘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 using private healthcare confirmed the lack of coordination—‘Doctors assume you are born with the knowledge to take care of yourself’ (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 could receive advice from a nutritionist, counselling for physiotherapy…’, ‘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’ experiences with the operationalisation of the main IPCHS substrategies

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.

<table>
<thead>
<tr>
<th>Patient characteristics</th>
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<tbody>
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<td>Age (years)</td>
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<td>63</td>
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</tbody>
</table>

This table lists patient characteristics including age, gender, country, healthcare system, and previous fragility fracture(s). The healthcare systems are categorized as universal, private, or public/private. The patients’ experiences with the operationalisation of the main IPCHS substrategies varied significantly between those with and without previous fragility fractures.
Patients with private healthcare perceived that the multifaceted 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).

Figure 2 Prioritisation of IPCHS substrategies based on patients’ experiences with osteoporosis care, according to healthcare system type. Yellow, ‘Empowering and engaging people and communities’ strategy; blue, ‘Reorienting the model of care’ strategy; green, ‘Coordinating services within and across sectors’ strategy; orange, ‘Creating an enabling environment’ strategy. IPCHS, Integrated, People-Centred Health Services.

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 if you don’t do something now, you will suffer in 10 or 20 years’ (Patient 17).

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 pharmaceutical 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’ substrategy and no difference in the experiences of patients with and without previous fragility fractures, likely because the main identified substrategies cover aspects of care relating to primary and secondary fracture prevention. The prioritisation of other substrategies differed among healthcare systems, reflecting the importance of the osteoporosis care context, but also showed substantial overlap, enabling the identification of substrategies 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 substrategy.

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.\textsuperscript{27} It requires the training of patients and health professionals, for whom the incorporation of patient counselling into consultations remains a challenge.\textsuperscript{28} Shared decision-making results in increased patient satisfaction, improved functional status, optimised self-management and better treatment adherence.\textsuperscript{27} but it requires comprehensive information about osteoporosis, therapeutic options and possible side effects. This information need has been reported,\textsuperscript{29,30} but its persistence is surprising, as two-thirds of this sub-strategy’s interventions have been operationalised in IOC.\textsuperscript{31} Furthermore, the effectiveness of different education programmes has been demonstrated.\textsuperscript{32}

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.\textsuperscript{33}

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.\textsuperscript{34–36} As did our interviewees, patients in Hawarden et al.’s\textsuperscript{30} study recommended a multidisciplinary care pathway for osteoporosis.

Multidisciplinary care pathways, such as FLSs, have been proven to cost-effectively reduce fracture rates.\textsuperscript{10,37} 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.\textsuperscript{38} 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.\textsuperscript{39} Considering the low cost of osteoporosis treatment relative to that of fracture treatment,\textsuperscript{40} a stronger primary care system may prevent overuse and misuse and reduce costs.\textsuperscript{41} Strong primary care-based systems may also be able to provide more regular follow-up, which effectively improves patient compliance and persistence with therapy.\textsuperscript{42} However, the number of primary care pathways for osteoporosis management remains limited.\textsuperscript{43}

In addition to being coordinated, fracture prevention services should cover the entire lifespan (‘defining 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\textsuperscript{44} and reflects the lack of awareness at public, clinical and policy levels,\textsuperscript{3} 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\textsuperscript{44} 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.\textsuperscript{45} Pregnant women should be made aware of bone health and supported in addressing their fetus’s needs,\textsuperscript{46} with an emphasis on achieving and maintaining the genetic potential peak bone mass.\textsuperscript{33} 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\textsuperscript{47} administration before further investigations, has been recommended.\textsuperscript{48}

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.\textsuperscript{49} Other research has demonstrated that national health coverage is cost-effective, improves population health and increases economic development.\textsuperscript{50} 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,\textsuperscript{51} but overall healthcare funding should be adequate.

\textbf{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.\textsuperscript{4} 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,52 experiences with specific programmes53 and attitudes toward treatment,54 or has been quantitative.55 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) (inter)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, conduct, analysis or publication decisions.

Competing interests
BL participates in meetings of the Global Coalition of Ageing as an expert, but has received no grant or fee for this participation. BL has received grants or fees from Amgen for consultancy, speaking and podcast activities. CV and RW have no competing interest to declare.

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/A2E6B.

Supplemental material
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