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Lived experiences and insights of Chinese patients with symptomatic osteoporosis on a patient-reported outcomes (PROs) program: A qualitative phenomenological study in Southwest China

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ABSTRACT

Objectives: To explore the lived experiences of patients with symptomatic osteoporosis on a patient-reported outcomes (PROs) program for symptom management and quality of life (QoL) improvement.

Design: This is a qualitative phenomenological study.

Setting: A regional osteoporosis care center.

Participants: Fourteen active participants in the PROs program were recruited and interviewed through semi-structured face-to-face interviews. Colaizzi's 7-step method was employed for thematic analysis.

Results: Four overarching themes and two sub-themes emerged including: (1) varied perceptions of the PROs program, where some participants found it beneficial for tracking symptoms while others cited challenges such as technological barriers and lack of actionable outcomes; (2) PROs as a tool for enhancing communication and facilitating appointments by enabling more efficient doctor-patient interactions and quicker scheduling; (3) emotional support provided by regular doctor-patient communication, with sub-themes of fostering a sense of belonging and offering psychological comfort; and (4) limitations of remote communication, highlighting challenges in addressing complex medical needs and providing immediate solutions for medication adjustments.

Conclusions: PROs programs facilitate symptom tracking, enhance communication, and provide emotional support for patients with osteoporosis. However, limitations such as technological barriers and reliance on remote communication must be addressed. Ethical considerations, including potential over-reporting of symptoms to expedite care, require careful management. Future research should include patients who discontinue participating in the PROs program prematurely and the perspectives of healthcare providers to provide a more balanced, comprehensive understanding.

Strengths and limitations of this study

- We employed a phenomenological approach for an in-depth exploration of the lived experiences of Chinese patients with symptomatic osteoporosis managed on a specialized patient-reported outcomes (PROs) program.
- The sample was limited to active participants in the PROs program, which potentially excluded insights from those who discontinued participation.

1. Background

Osteoporosis is a systemic skeletal disorder characterized by compromised bone strength, predisposing individuals to an increased risk of fractures [1]. With a global prevalence of 18.3%, the overall prevalence of osteoporosis in China is 20.8%, with a higher prevalence in women (23.7%) than in men (12.7%) [2,3]. The standardized prevalence of osteoporosis in mainland China ranges from 5.0% to 7.5% in males aged ⩾50 years and from 26.3% to 39.2% in females aged ⩾50 years, respectively [4]. Its prevalence has been increasing over the recent years in both China and other countries [2,5-7]. This condition significantly impacts the quality of life, primarily through pain, decreased mobility, and the fear of sustaining fractures, leading to a cycle of physical inactivity, social isolation, and psychological distress [8-10].

The management of chronic conditions such as osteoporosis has increasingly recognized the value of incorporating patient-reported outcomes (PROs) [11,12]. PROs, which encompass any report of the status of a patient's health condition coming directly from the patient, without interpretation of the patient's response by a clinician or anyone else, offer invaluable insights into the patient's perceived health status, treatment efficacy, and overall well-being [13]. In osteoporosis, where the subjective experience of pain and mobility constraints critically influences disease management and therapeutic outcomes, PROs serve as essential tools in tailoring patient-centered care strategies, enhancing patient engagement, and optimizing treatment outcomes.

Despite the known benefits of PROs in chronic disease management, their integration into the clinical routine for osteoporosis remains inconsistent. Patients with osteoporosis face multifaceted challenges in managing their symptoms and overall quality of life [14]. The complexity of

symptom management is compounded by the silent nature of the disease until a fracture occurs, often leading to delayed diagnosis and intervention [15,16]. Moreover, the fear of fracture can significantly limit physical activity, contributing to a decline in physical health and further exacerbating the risk of additional osteoporotic fractures [8,17].

The existing gap in comprehensive symptom and quality of life management in osteoporosis care, coupled with the underutilized potential of PROs, underscores a critical need for a deeper exploration into patient experiences. Understanding the lived experiences of patients with osteoporosis, through the lens of PROs, is imperative in identifying barriers to effective management and unveiling opportunities to improve care delivery and patient outcomes.

The primary aim of this research is to explore the symptomatic patients' experiences in using PROs for improving symptom management and quality of life (QoL). By delving into the nuanced perspectives of patients, we sought to uncover the multifaceted role that PROs can play in a clinical setting, focusing on their capacity to offer a more personalized, responsive, and effective approach to managing the complex symptomatology associated with osteoporosis. Our findings can inform more empathetic, patient-centric care models to address both the physical and psychological and social facets of the condition that profoundly affect patients' well-being.

2. Methods

2.1. Study design

This is a qualitative phenomenological study. We conducted semi-structured in-depth interviews face to face with patients with symptomatic osteoporosis, who were managed on a PROs program at our hospital. Colaizzi's methodology was employed for thematic analysis [18].

2.2. Setting

This work was conducted at the West China Fourth Hospital, located in Chengdu, the capital city of Sichuan province in Southwest China. Our Osteoporosis Care Department is one of the largest care-providers in the region, dedicated to the management and treatment of osteoporosis. Annually, the care center receives nearly 3,000 outpatient visits and about 3500 inpatients.

2.3. PROs Program

Our Osteoporosis PROs Management Program was launched in 2021, which aims to use PROs for management of osteoporosis symptoms and enhance patients' QoL. We employ an in-house developed PROs questionnaire, including a symptom scale, a QoL scale, and a condition diary for patients to assess and record their experiences, symptoms, and the overall impact of osteoporosis on their daily lives.

The program is exclusively available to patients with symptomatic osteoporosis aged 50-80 years from both genders. Those with significant psychological or physical conditions, such as serious depression or malignant tumors, are excluded.

Participants in the program are encouraged to actively record their symptoms, QoL, and any significant osteoporosis-related experiences. The records are then submitted to a designated follow-up manager by phone or online. The manager is typically a physician or nurse, who is responsible for reviewing the information and providing personalized recommendations.

The follow-ups, typically occurring every 7-14 days, are for record collection and rapid assessment. Based on the findings, non-medication or non-invasive recommendations are offered to address the symptoms and challenges documented by the patients. In case of significant or concerning records, patients are advised to seek immediate medical attention. Patients may also

present their PROs records on their next followup visits for physician consideration.

2.4. Participants

We selected participants for the current study from the active patients on our PROs program. Patients were enrolled if aged 50-80 yrs, having a confirmed diagnosis of osteoporosis, with or without osteoporotic fracture, reporting symptoms related to osteoporosis such as pain or reduced mobility, having adequate cognitive and communication capacity, and capable of providing informed consent and participating in a 20-40 min face-to-face interview.

Those, who were aged <50 or >80 yrs, had fracture(s) known not to be attributed to osteoporosis such as fracture from a car accident, had a known psychological or physical condition that might affect the results of our current study such as other chronic diseases with unmanaged symptoms, had inadequate cognitive or communication capacity, or were unable to give consent or participate in an interview, were excluded.

The researchers screened for potential participants to the study by reviewing the medical records and PROs management files of patients on the PROs program to determine eligibility. On the initial contact to recruit participants, the researchers visually assessed their mental status and communication capacity.

2.5. Sampling

Purposive sampling was used to enroll participants between January 7, 2024 through February 10, 2024. A researcher accessed the medical records of the current participants on the PROs program to select potential participants and approached them on one of their followup visits.

The researcher first assessed their physical and mental status and communication ability through a casual conversation. If suited, the participants were asked if they were willing to participate in this

study. If yes, the researchers explained the purpose, process, and expected use of the results. If the patient agreed to participate, they were requested to stay for a 20-40 min face-to-face interview after their consultation session. Another researcher might perform the interview if the earlier researcher was unavailable. Interviewers were trained on semi-structured face-to-face interview techniques and familiarized with the interview guide.

2.6. Face-to-face interview

We developed an semi-structured interview guide with open questions (Supplemental Material 1). Interviews were made in a designated room, which was a private quiet environment. Only one participant was interviewed at a time. Any support person or carer was requested to stay outside the interview room. The sampling process continued until data saturation was reached, where two consecutive interviews failed to yield any new analytical information, as determined on consensus of the research team [19].

2.7. Procedure

All researchers were either active care-providers on the PROs program or healthcare professionals of relevant specialties, who had received training in phenomenological research methods and semi-structured interview. Interviews were about 13 min on average (11-19 min), which were recorded using the recorder app on the researcher's smartphone.

The initial inquiry in each interview session was posed as a broad, open-ended question, such as 'Could you tell me your experiences related to your osteoporosis recently?' or 'How has your life been impacted since being diagnosed with osteoporosis?' to encourage participants to freely express themselves.

To delve deeper participants' experiences, probing questions such as "Could you elaborate on that

experience?" or "Can you describe in more detail how that aspect affected you?" were employed to stimulate further reflection and detail, allowing for a comprehensive exploration of the lived experiences of individuals with osteoporosis.

Throughout the interview process, the researcher utilized various techniques to enhance the depth of the conversation and ensure the authenticity of the responses, such as rhetorical questioning to provoke thought, repetition for emphasis and clarification, and reflective responses to demonstrate understanding and empathy towards the participants' experiences.

The researcher took field notes during each interview, capturing crucial non-verbal cues such as changes in the participant's tone of voice, facial expressions, and body gestures, to provide valuable context to the verbal responses. The audio recording of each interview was cataloged and transcribed verbatim by one researcher and reviewed for accuracy by a different researcher in 24 hrs.

To protect participant privacy and confidentiality, all personal identifiers were removed from the transcripts and notes. Participants were numbered as Participant 1, 2, 3... All data, including audio recordings, transcripts, and field notes, were extracted from researchers' smartphone app and stored on two password-protected flash drives. Access to all study materials was strictly limited to members of the research team.

2.8. Rigour and reflexivity

We took strategies to ensure rigor throughout our study, including providing sufficient interview time to gain an in-depth understanding of the phenomenon and to identify and account for any anomalies; cross-verifying our findings, for example, using participants' PROs records; returning all results to participants for validation; involving multiple researchers in the coding process to

mitigate individual biases; and discussing discrepancies in coding to reach a consensus on themes and interpretations. For discrepancies unresolved through discussion, the researcher reached out for participant clarification by phone.

To address reflexivity, we implemented several measures to minimize potential bias. All researchers underwent pre-study training on reflexivity to raise awareness of how personal beliefs and professional backgrounds could influence the study. A reflexivity statement was written as a reminder for the research team, which stresses the importance of maintaining critical self-awareness throughout the process (Supplemental Material 2). We held a main meeting at the start of the study, where researchers reflected on their backgrounds, beliefs, and potential influences on the study and findings. Additionally, reflexivity was a designated discussion point in regular team meetings. We also documented key decisions in the research process.

2.9. Data analysis

We used the Colaizzi's 7-step method for data analysis [18]. First, we immersed in the data by reading all participants' descriptions repeatedly to gain a sense of the overall experience. Key phrases or sentences directly relating to the phenomenon were extracted. Each significant statement was analyzed to derive meanings, which were then grouped into thematic clusters. We then developed an exhaustive description of the phenomenon by integrating all the themes to capture the essence of the participants' lived experiences. The exhaustive description was then synthesized to articulate the fundamental structure of the phenomenon by summarizing the essence of the experience into a concise narrative, which was validated with the participants, ensuring that our analysis accurately reflected their experiences.

2.10. Ethical consideration and informed consent

This study was approved by the Ethics Committee of West China Fourth Hospital, Sichuan University (Approval number 23011). Written informed consents were attained from all participants before interview.

2.11. Patient and public involvement

None.

3. Results

3.1. Demographic and clinical data

Before data saturation was achieved, we approached 14 patients, who agreed to take the interview (100.%). The participants were aged 67.7 years on average (age range, 55-78). Most of them were women (n=10, 71.4%). Their education levels were generally low, with a majority being junior high school or below (n=9, 64.3%). Their symptoms due to osteoporosis varied. The most commonly reported symptom was limited mobility (n=14, 100%), followed by chronic pain (n=10, 71.4%) and weight loss (n=8, 57.1%). Eight participants had one or more fractures, including 4 with multiple fractures (28.6%). All of them had been on the PROs program for an extended period of at least 6 months by the time of interview. (Table 1)

Table 1. Demographic and clinical characteristics (N=14)

Characteristic	**Category**	***n***	**%**
Gender	Female	10	71.4
	Male	4	28.6
Age (years)	50-60	5	35.7
	60-70	5	35.7
	70-80	4	28.6

Education level	Primary school	3	21.4
	Junior high	6	42.9
	Senior high	3	21.4
	College or over	2	14.3
Main symptoms	Chronic pain	10	71.4
	Severe bone pain	5	35.7
	Low back pain	5	35.7
	Weight loss	8	57.1
	Limited mobility	14	100.0
	Stooped posture	3	21.4
Fracture	No fracture	6	42.9
	1 fracture	4	28.6
	⩾2 fractures	4	28.6
Time on PROs (months)	6-8	7	50.0
	9-12	4	28.6
	⩾13	3	21.4

Note: PROs, patient-reported outcomes.

3.2. Themes

We summarized four overarching themes and two sub-themes from our interviews with the participants.

3.2.1. **Overarching theme 1: Varied perceptions of the PROs program**

A prominent theme emerging from our interviews was the significant diversity in participants' attitudes and feelings towards the use of PROs. On one hand, some participants expressed positive response and enthusiasm that the PROs program was extremely beneficial for them:

Quote 1: "I think the PROs program is really great. It helps me record my daily physical condition and pain levels in detail, so I can clearly communicate this to my doctor during visits,

aiding them in adjusting my treatment plan more accurately." (Participant 1)

- Quote 2: "Filling out the PRO questionnaires regularly allows me to better understand the progression of my condition. It helps to improve my symptoms and quality of life. This has been very helpful for managing my condition on my own." (Participant 4)

However, on the other hand, some other participants reported that the PROs program was not particularly helpful:

- Quote 3: "Although I understand that PRO programs are meant to reflect my actual condition, sometimes filling out these forms feels cumbersome, and it seems like they don't immediately improve my symptoms." (Participant 2)

- Quote 4: "I'm not sure if the doctors are really making adjustments based on the PRO data I show them. Sometimes it feels more like a formality, without really having an effect." (Participant 7)

- Quote 4: "Helpful but difficult sometime. I'm not skilled with a (smart) phone. Also, the forms are complicated." (Participant 9)

3.2.2. Overarching theme 2: Enhancing communication and facilitating appointments

An interesting phenomenon highlighted in our interviews was that one of the motivating factors for many patients' continued participation in PRO programs was to use it as an efficient way to communicate their medical conditions with healthcare professionals, especially to help in faster scheduling of appointments with specialists:

- Quote 1: "One reason I keep filling out the PRO forms is because I feel it allows me to frequently and directly let the doctors know about the progress of my condition. It was impossible before without it (the PROs program)." (Participant 3)

- Quote 2: "By submitting the (PROs) forms, I feel that the hospital people can notice changes in my condition more quickly... The waiting time (for appointments) has shortened after reporting symptoms." (Participant 6)

Furthermore, some humorous remarks reflected some of their helpless actions in the real medical environment:

- Quote 3: "Haha, sometimes I wonder if making my symptoms sound a bit more severe could get me an appointment faster. Of course, I know it's not the right thing to do, but it's difficult to get an appointment quickly." (Participant 3)

- Quote 4: "I do believe that by filling out the PRO forms in detail and carefully, at least the doctors know I urgently need their help. To some extent, it seems like 'the more severe the condition, the faster the appointment.'" (Participant 9)

3.2.3. Overarching theme 3: Emotional support through regular interaction

The interview findings revealed that many patients valued the regular one-on-one communication with healthcare professionals. The opportunity to discuss their conditions in detail every one or two weeks had a positive impact on their emotional comfort and psychological support, especially during times of worsening illness:

Sub-theme 1: Building a sense of belonging

In the interviews, two patients mentioned the word "sense of belonging", indicating strong emotional support and fulfillment to some extent.

- Quote 1: "After joining the PRO program, I felt like I was not just a patient but a part of the care team for myself. The feeling of being noticed and understood gave me a strong sense of belonging." (Participant 2)

- Quote 2: "Whenever I submit my condition report, they (followup manager) always respond quickly, making me feel like that someone cares about me and giving me a sense of belonging." (Participant 11)

Sub-theme 2: Providing reassurance and comfort

Three participants emphasized a similar viewpoint, which was that even though the PRO programs might not have immediately changed their actual symptoms, the continuous attention to their condition by healthcare professionals and the professional advice obtained through PRO programs were valuable, which provided them significant inner relief and support:

- Quote 1: "Even though my symptoms are mostly manageable most of the time, knowing that someone is always closely monitoring my condition gives me a sense of security that I am not enduring the pain alone." (Participant 5)

- Quote 2: "Even if the advice is sometimes just simple precautions or lifestyle adjustments, this attention and guidance from professionals reassure me that I am managing my condition correctly, which itself is a great psychological support." (Participant 8)

- Quote 3: "Every time I complete a PRO report and receive responses and suggestions from healthcare professionals, it's like injecting a tranquilizer into my heart, making me realize I'm a scientific method to fight the disease." (Participant 9)

3.2.4. Overarching theme 4: Limitations of remote communication for complex needs

One common feedback from our interviews was that though the participants acknowledged the convenience and attention provided by regular online and telephonic communication modes, they also pointed out the limitations of these methods, primarily regarding the inability to prescribe medications and offer in-depth therapeutic intervention advice:

- Quote 1: "I appreciate being able to communicate regularly with healthcare professionals via phone or online, but when if I need specific medication adjustments, it can't be done (online or by phone). (I) still have to go to see a doctor for prescriptions." (Participant 5)

- Quote 2: "(They give) some basic advice, but for complex conditions or the need to adjust treatments, mere phone or online communication is infeasible." (Participant 6)

- Quote 3: "My disease is complex. Face-to-face examination and in-depth diagnosis by the doctor are really needed. Just relying on a few short sentences over the phone, it's not enough, especially can't prescribe medications by phone." (Participant 9)

- Quote 4: "More convenient than without it (PROs program), but still feels like a building in the air. For example, when my condition worsens at home and there's an urgent need to adjust medication dosages or switch medications, I can't do it through phone even if I report it by communicating with the health professional (on the PROs program). Still have to wait until the next clinic visit, though appointment is indeed faster." (Participant 12)

In summary, participants reported a spectrum of experiences with the PROs program, which reflected both its benefits and challenges. While the program facilitated symptom tracking, enhanced communication, and provided emotional support, they also identified significant barriers, including technological difficulties and the limitations of remote communication in addressing complex medical needs.

4. Discussion

PROs have been increasingly recognized and adopted in managing chronic diseases. These tools provide healthcare professionals with direct insights into patients' subjective experiences,

symptom burdens, and the impact of illness on their daily lives, thereby enriching clinical decision-making with a more holistic view of patient well-being [20]. In the context of osteoporosis, a condition often characterized by silent progression and acute symptomatic episodes, PROs can play a crucial role in identifying subtle changes in patient condition, from monitoring treatment effectiveness to facilitating timely interventions [21]. Our findings suggest that PROs can capture the nuanced experiences of patients with osteoporosis, which helps in tailoring treatment plans to individual needs and potentially enhancing patient engagement and satisfaction, consistent with prior reports on other conditions [22-24].

Our interviews with symptomatic patients with osteoporosis on a PROs program for symptom management and QoL improvement yielded enriching findings about various aspects of PROs adoption in realistic settings. According to Theme 1, patients perceived use of PROs differently, which reflects a critical aspect of patient-centered healthcare, individual variability in response to health interventions [25]. Our findings reveal a spectrum of experiences with PROs, including both potential benefits and challenges.

Positive feedback from participants emphasizes the value of PROs in enhancing doctor-patient communication and self-management of the condition, which resonates with Theme 2 where participants find PROs bridging doctor-patient communication. These patients perceive PROs as a tool that facilitates a more accurate and detailed representation of their health status and also empowers them to take an active role in their care. This aligns with existing literature that suggests PROs can improve the quality of care by providing clinicians with a more comprehensive understanding of patients' experiences, potentially leading to more tailored and effective treatment plans [26,27].

In contrast, the challenges highlighted by other participants point to significant barriers in the implementation and utility of PROs. These include the perceived burden of completing the forms, doubts regarding the clinical integration of PRO data, and accessibility issues, particularly related to technology use. Such concerns are reflective of broader issues in the development and deployment of PROs, where the design, complexity, and integration into clinical workflows can significantly impact their effectiveness and patient engagement, which might echo with past lessons learned in designing and implementation of clinical services [28-30].

The variation in patient perceptions of PROs necessitates a more tailored approach to their implementation and use within clinical settings. Simplification of the PRO tools and making them more user-friendly for patients of varying technological proficiencies may ensure that the data collected using these tools are better encouraged and complied with. To effectively implement PROs in clinical practice, healthcare providers should prioritize tailoring the tools to accommodate the diverse needs and preferences of patients. For example, simplifying the forms, providing clear instructions, and offering technical support can reduce the burden on patients, particularly those with limited technological proficiency.

The effect of PROs to bridge doctor-patient communication is well documented [31,32]. Participants' narratives reveal that PROs serve as a tool for symptom tracking and health reporting as well as significantly an effective communication channel between patients and healthcare providers. As exemplified by Participant 3, the ability to frequently and directly inform doctors about the progression of one's condition was perceived as a novel and empowering aspect of care that was previously unattainable. Healthcare providers can establish structured feedback loops where PROs data are regularly reviewed and discussed with patients. This approach not only

validates the effort patients put into reporting their symptoms but also strengthens the doctor-patient relationship.

Moreover, the participants' comments also shed light on the pragmatic strategies some patients employ to navigate the often fraught and congested pathways to receiving timely medical attention. For instance, Participant 3's humorous yet poignant admission of exaggerating symptoms to expedite appointment scheduling underscores a broader issue of access to care, a challenge that PROs can inadvertently help mitigate by providing a more immediate and transparent depiction of patient needs.

However, it must be noted that the current arrangements within the PROs program to expedite appointment scheduling pose a risk of patients potentially over-reporting their conditions. This unintended consequence highlights a critical area for careful consideration and calibration in the implementation of PRO systems.

While the immediacy and transparency afforded by PROs are invaluable for enhancing communication and streamlining care pathways, they also introduce the possibility of skewed data due to patients, as noted by some participants, possibly exaggerating symptoms to secure faster medical attention. This phenomenon, while understandable from the patient's perspective, especially in the face of long wait times and perceived barriers to accessing care, could lead to inefficiencies and misallocations of healthcare resources as well as misinformed clinical decisions. This raises important ethical and practical questions about how to maintain the integrity and accuracy of patient-reported data while ensuring that the system remains responsive and equitable.

To mitigate such risks, it is imperative that healthcare providers engage in regular validation checks and foster open, trust-based relationships with patients, such as this qualitative

investigation, to encourage honest and accurate reporting. Also, education and communication strategies can emphasize the importance of accurate symptom reporting, highlighting how over- or under-reporting can impact their own care. Healthcare providers should invest in patient education initiatives to improve the accuracy and reliability of PROs data, including training patients to understand the importance of honest reporting and guiding them on how to effectively use the tools.

Addressing these challenges requires a delicate balance between leveraging the benefits of PROs for enhanced patient-centered care and safeguarding against potential pitfalls associated with self-reported health information [33,34]. As the healthcare landscape continues to evolve with greater digitalization, ongoing research and dialogue among clinicians, patients, and policymakers will be crucial in refining PRO programs to serve as effective, efficient, and ethical tools in patient care and health system management.

The interview findings compellingly illustrate the profound emotional support and psychological comfort that regular doctor-patient communication, facilitated through the PROs program, which is consistent with existing reports on use of PROs [35,36]. The consistent and personalized interaction, through weekly chats on followup reporting and calls, serves as a medium for medical consultation as well as a significant source of emotional support. Furthermore, the mentioning of a "sense of belonging" by participants reflects the transformation of the patient role from a passive recipient to an active member of the healthcare team. Participants articulated that beyond management of physical symptoms, the knowledge that their condition was under constant surveillance and the receipt of timely, personalized advice acted as a psychological buffer against the isolation and anxiety that chronic conditions often engender.

These insights reveal that the value of PROs programs extends far beyond their immediate clinical utility. By fostering regular, meaningful communication between patients and healthcare providers, PROs programs contribute significantly to the emotional and psychological well-being of patients, reinforcing the indispensable role of empathy and support in the treatment of chronic conditions such as osteoporosis [37].

Theme about the limitations of remote communication channels such as phone and online platforms in addressing more nuanced and complex medical needs may be an inherent challenge with PROs initiatives. Participant 5's experience showcases a common scenario where the ease of remote communication is appreciated for its regularity and accessibility but is simultaneously constrained by regulatory and practical limitations around prescribing medications, which impedes timely management of the reported condition and necessitates in-person visits.

Similarly, Participants 6 and 9 articulate the challenges faced when complex conditions or treatment adjustments are involved. The intricacies of managing a chronic condition such as osteoporosis often require detailed examinations and in-depth discussions that are difficult, if not infeasible, to replicate through remote interactions. The lack of physical examination and direct patient observation can lead to gaps in clinical assessment and decision-making, potentially affecting the quality of care.

Furthermore, Participant 12's comment represents the frustration experienced by patients when urgent medical needs arise, and the limitations of remote communication become apparent. The scenario described, a patient's condition worsening at home with an immediate need for medication adjustments, illustrates a critical juncture where the PROs program's utility is challenged by the inability to provide real-time, actionable medical interventions.

These reflections emphasize the necessity for a balanced approach to healthcare delivery, one that leverages the advantages of remote communication for regular monitoring and patient engagement while recognizing and addressing its limitations through integrated care models. Such models should seamlessly combine remote and in-person care services, ensuring that patients receive comprehensive, timely, and effective care, particularly for conditions requiring close management and frequent adjustments. Bridging this gap is essential for maximizing the potential of PROs programs in enhancing patient care and outcomes in the management of chronic diseases such as osteoporosis. To address the limitations, healthcare providers may consider hybrid care models combining remote monitoring with in-person visits. For instance, periodic in-person reviews, not necessarily occurring during clinical visits but designated sessions of the PROs program, could complement remote symptom tracking. This can ensure that complex medical needs are better addressed.

Limitations

Two main limitations of our study should be noted. Firstly, our participant selection criteria, which included individuals who had been actively participating in the PROs program for six months or longer, inherently skews our sample towards patients who are potentially more motivated and engaged with their healthcare management. This selection criterion may inadvertently exclude insights from a significant subset of patients who discontinued the PROs program prematurely. Their perspectives remain unexplored and reported in our study and could provide valuable insights into potential shortcomings or challenges of PROs programs such as ours. Secondly, this study focused only on the experiences of patients using PROs and did not

include healthcare providers who interact with and act upon the PRO data, who play a vital role in interpreting PROs, integrating them into clinical decisions, and providing feedback to patients. Including them in future research would allow for a more balanced and comprehensive understanding of how PROs influence patient care and decision-making.

5. Conclusions

PROs programs facilitate symptom tracking, enhance communication, and provide emotional support for patients with osteoporosis. However, limitations such as technological barriers and reliance on remote communication must be addressed. Ethical considerations, including potential over-reporting of symptoms to expedite care, require careful management. Future research should include patients who discontinue participating in the PROs program prematurely and the perspectives of healthcare providers to provide a more balanced, comprehensive understanding.

AI use statement

ChatGPT was used to translate the original Chinese text and refine the English language in the final draft. It was not used in designing or implementing the study, interpreting the findings, or writing of the manuscript draft.

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Contributorship statement

YC and LS conceptualized and designed the study and conducted the interviews; YZ and QZ transcribed the audio recordings; LS verified the transcripts; YC, YZ, QZ, and LS analyzed the data and interpreted the themes; YC drafted the initial manuscript. All authors reviewed and approved the final version for submission and agree to be accountable for all aspects of the work. LS is responsible for the overall content as guarantor.

Competing interests

No competing interest.

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Data sharing statement

The original audio recordings are not to be shared due to institutional privacy protection policy. The PROs questionnaire and data analyzed in the current study are available on reasonable request to the corresponding author.

Ethics approval

This study was approved by the Ethics Committee of West China Fourth Hospital, Sichuan University (Approval number 23011).

Consent to participate

Informed consents were attained from all participants before interview.

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Supplemental Material 1: Semi-structured Interview Guide

Introduction

- Self-introduction
- Briefly explain the study again and the interview
- Emphasize confidentiality and voluntary participation
- Verbally obtain permission for recording the interview
- Allow the participant to ask questions if any

Interview

Start with a general question to break ice:

- Could you tell me your experiences related to your osteoporosis recently? or
- How has your life been impacted since being diagnosed with osteoporosis?

1. General experience

- **Main question**: Could you elaborate on that experience?/Can you describe in more detail how that aspect affected you?
    - Probing questions to relate to the PROs program:
        - What was your motivation to participate in the program in the first place?
        - How were your first impressions of the program?
        - Can you explain that?
        - Why do you think so?

2. Ease of use and accessibility of PROs program

- **Main question**: How easy or difficult is it for you to use the PROs program?
    - Probing questions:
        - Can you walk me through how you typically complete the PROs forms or reports?

- Are there any aspects of the forms that you find particularly clear or confusing?
- Have you experienced any technical challenges, such as difficulty using a phone or computer?

3. Impact on symptom management

- **Main question**: How has the PROs program helped you manage your symptoms?
  - Probing questions:
    - Have you noticed any changes in how you track or understand your symptoms since joining the program?
    - Can you give an example of a time when the program helped you manage a specific symptom or situation?
    - Are there any symptoms or issues that the program does not address well?

4. Communication with healthcare providers

- **Main question**: How has participating in the PROs program affected your communication with your doctor or nurse?
  - Probing questions:
    - Do you feel the program helps you communicate your symptoms more effectively? How?
    - Can you recall a specific instance where the program facilitated better communication or care?
    - Do you think healthcare providers fully understand and act on the information you provide through the program?

5. Emotional and psychological impact

- **Main question**: How has the PROs program affected your emotional well-being or sense of support?

- Probing questions:
    - Does participating in the program make you feel more connected to your healthcare team? Why or why not?
    - Have you found the program to be a source of emotional comfort or support? Can you explain?
    - Are there any emotional challenges you've faced while using the program?

6. Benefits of the program

- **Main question**: What do you think are the main benefits of the PROs program?
    - Probing questions:
        - Are there specific aspects of the program that have positively impacted your quality of life?
        - Do you think the program has made managing your condition easier? Why or why not?
        - Would you recommend the program to others? Why?

7. Challenges and limitations

- **Main question**: Have you faced any challenges or limitations with the PROs program?
    - Probing questions:
        - Are there any parts of the program that you find frustrating or unhelpful?
        - Do you think the program meets all your needs? If not, what is missing?
        - Can you share any specific instances where the program didn't work well for you?

8. Suggestions for improvement

- **Main question**: If you could make changes to the PROs program, what would they be?
    - Probing questions:
        - Are there features you think should be added to the program?

- How could the program be made more convenient or accessible for you?
- Are there any ways the follow-up process could be improved?

9. Long-term use and sustainability

- **Main question**: Do you see yourself continuing to use the PROs program in the future? Why or why not?
  - Probing questions:
    - What keeps you motivated to continue using the program?
    - Are there factors that might make you stop participating in the program?
    - How do you see the program fitting into your long-term care plan?

10. Additional thoughts

- **Main question**: Is there anything else you would like to share about your experiences with the PROs program?
  - Probing questions:
    - Do you feel like we've covered all the important aspects of your experience?
    - Is there anything you feel we should know to better understand the program's impact?

11. End of interview

Thank participant. Offer them a chance to ask questions or share final thoughts.

12. Notes

(1) Ensure the interview setting is private, quiet, and comfortable to help participants feel at ease.

(2) Adjust probing questions based on the participant's responses to encourage depth but don't try to lead the conversation. No need to ask all the questions in the interview guide. However, make sure sufficient meaningful information is obtained.

(3) Pay attention to participant's body language, tone of voice, and facial expressions, noting them for context.

Supplemental Material 2: Reflexivity Statement

English Translation:

Reflexivity Statement

As we embark on this study, it is essential to remain critically aware of our potential influences on the research process and findings. Each of us brings unique cultural, professional, and personal perspectives that could shape how we design the study, collect data, and interpret results.

We recognize that our roles as healthcare professionals specializing in osteoporosis management, along with our shared belief in the value of PROs, may lead us to approach the research with certain assumptions. These include an inherent focus on the benefits of PROs and potential biases in interpreting participants' experiences.

To mitigate these influences, we commit to:

1. Maintaining a reflexive journal to document thoughts, assumptions, and decision-making processes throughout the study.
2. Engaging in open and critical discussions about reflexivity during team meetings to challenge each other's perspectives and interpretations.
3. Actively reflecting on how our professional backgrounds, cultural contexts, and values may shape the questions we ask, the way we interact with participants, and the conclusions we draw.
4. Prioritizing the voices of participants in our analysis and ensuring their experiences guide the findings, rather than our preconceptions.

This statement serves as a constant reminder to critically examine our roles and maintain transparency and rigor in all aspects of the research.

Chinese Original:

反思声明

在开展本研究过程中，保持对我们自身对研究过程和结果潜在影响的批判性意识至关重要。我们每个人都带着独特的文化、专业和个人视角，这可能会影响我们设计研究、收集数据和解释结果的方式。

我们认识到，作为专注于骨质疏松管理的医疗专业人员，以及我们对 PROs 价值的共同信念，可能使我们在研究中带有某些假设。这些假设包括对 PROs 益处的固有关注，以及在解读参与者经历时可能存在的偏见。

为减少这些影响，我们承诺：

1. 在整个研究过程中保持反思性日志，记录思考、假设和决策过程。
2. 在团队会议中进行开放和批判性的反思性讨论，以挑战彼此的观点和解释。
3. 积极反思我们的专业背景、文化环境和价值观如何影响我们提出的问题、与参与者互动的方式以及我们得出的结论。
4. 在分析中优先考虑参与者的声音，确保他们的经历引导研究结果，而非我们的先入之见。

此声明旨在时刻提醒我们，批判性地审视自己的角色，并在研究的各个方面保持透明性和严谨性。

BMJ Open

Lived experiences and insights of Chinese patients with symptomatic osteoporosis on a patient-reported outcomes (PROs) program: A qualitative phenomenological study in Southwest China

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Lived experiences and insights of Chinese patients with symptomatic osteoporosis on a patient-reported outcomes (PROs) program: A qualitative phenomenological study in Southwest China

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ABSTRACT

Objectives: To explore the lived experiences of patients with symptomatic osteoporosis on a patient-reported outcomes (PROs) program for symptom management and quality of life (QoL) improvement.

Design: This is a qualitative phenomenological study.

Setting: A regional osteoporosis care center.

Participants: Fourteen active participants in the PROs program were recruited and interviewed through semi-structured face-to-face interviews. Colaizzi's 7-step method was employed for thematic analysis.

Results: Four overarching themes and two sub-themes emerged including: (1) varied perceptions of the PROs program, where some participants found it beneficial for tracking symptoms while others cited challenges such as technological barriers and lack of actionable outcomes; (2) PROs as a tool for enhancing communication and facilitating appointments by enabling more efficient doctor-patient interactions and quicker scheduling; (3) emotional support provided by regular doctor-patient communication, with sub-themes of fostering a sense of belonging and offering psychological comfort; and (4) limitations of remote communication, highlighting challenges in addressing complex medical needs and providing immediate solutions for medication adjustments.

Conclusions: PROs programs facilitate symptom tracking, enhance communication, and provide emotional support for patients with osteoporosis. However, limitations such as technological barriers and reliance on remote communication must be addressed. Ethical considerations, including potential over-reporting of symptoms to expedite care, require careful management. Future research should include patients who discontinue participating in the PROs program prematurely and the perspectives of healthcare providers to provide a more balanced, comprehensive understanding.

Strengths and limitations of this study

- We employed a phenomenological approach for an in-depth exploration of the lived experiences of Chinese patients with symptomatic osteoporosis managed on a specialized patient-reported outcomes (PROs) program.
- The sample was limited to active participants in the PROs program, which potentially excluded insights from those who discontinued participation.

1. Background

Osteoporosis is a systemic skeletal disorder characterized by compromised bone strength, predisposing individuals to an increased risk of fractures [1]. With a global prevalence of 18.3%, the overall prevalence of osteoporosis in China is 20.8%, with a higher prevalence in women (23.7%) than in men (12.7%) [2,3]. The standardized prevalence of osteoporosis in mainland China ranges from 5.0% to 7.5% in males aged ⩾50 years and from 26.3% to 39.2% in females aged ⩾50 years, respectively [4]. Its prevalence has been increasing over the recent years in both China and other countries [2,5-7]. This condition significantly impacts the quality of life, primarily through pain, decreased mobility, and the fear of sustaining fractures, leading to a cycle of physical inactivity, social isolation, and psychological distress [8-10].

The management of chronic conditions such as osteoporosis has increasingly recognized the value of incorporating patient-reported outcomes (PROs) [11,12]. PROs, which encompass any report of the status of a patient's health condition coming directly from the patient, without interpretation of the patient's response by a clinician or anyone else, offer invaluable insights into the patient's perceived health status, treatment efficacy, and overall well-being [13]. In osteoporosis, where the subjective experience of pain and mobility constraints critically influences disease management and therapeutic outcomes, PROs serve as essential tools in tailoring patient-centered care strategies, enhancing patient engagement, and optimizing treatment outcomes.

Despite the known benefits of PROs in chronic disease management, their integration into the clinical routine for osteoporosis remains inconsistent. Patients with osteoporosis face multifaceted challenges in managing their symptoms and overall quality of life [14]. The complexity of

symptom management is compounded by the silent nature of the disease until a fracture occurs, often leading to delayed diagnosis and intervention [15,16]. Moreover, the fear of fracture can significantly limit physical activity, contributing to a decline in physical health and further exacerbating the risk of additional osteoporotic fractures [8,17].

The existing gap in comprehensive symptom and quality of life management in osteoporosis care, coupled with the underutilized potential of PROs, underscores a critical need for a deeper exploration into patient experiences. Understanding the lived experiences of patients with osteoporosis, through the lens of PROs, is imperative in identifying barriers to effective management and unveiling opportunities to improve care delivery and patient outcomes.

The primary aim of this research is to explore the symptomatic patients' experiences in using PROs for improving symptom management and quality of life (QoL). By delving into the nuanced perspectives of patients, we sought to uncover the multifaceted role that PROs can play in a clinical setting, focusing on their capacity to offer a more personalized, responsive, and effective approach to managing the complex symptomatology associated with osteoporosis. Our findings can inform more empathetic, patient-centric care models to address both the physical and psychological and social facets of the condition that profoundly affect patients' well-being.

2. Methods

2.1. Study design

This is a qualitative phenomenological study. We conducted semi-structured in-depth interviews face to face with patients with symptomatic osteoporosis, who were managed on a PROs program at our hospital. Colaizzi's methodology was employed for thematic analysis [18].

2.2. Setting

This work was conducted at the West China Fourth Hospital, located in Chengdu, the capital city of Sichuan province in Southwest China. Our Osteoporosis Care Department is one of the largest care-providers in the region, dedicated to the management and treatment of osteoporosis. Annually, the care center receives nearly 3,000 outpatient visits and about 3500 inpatients.

2.3. PROs Program

Our Osteoporosis PROs Management Program was launched in 2021, which aims to use PROs for management of osteoporosis symptoms and enhance patients' QoL. We employ an in-house developed PROs questionnaire, including a symptom scale, a QoL scale, and a condition diary for patients to assess and record their experiences, symptoms, and the overall impact of osteoporosis on their daily lives.

The program is exclusively available to patients with symptomatic osteoporosis aged 50-80 years from both genders. Those with significant psychological or physical conditions, such as serious depression or malignant tumors, are excluded.

Participants in the program are encouraged to actively record their symptoms, QoL, and any significant osteoporosis-related experiences. The records are then submitted to a designated follow-up manager by phone or online. The manager is typically a physician or nurse, who is responsible for reviewing the information and providing personalized recommendations.

The follow-ups, typically occurring every 7-14 days, are for record collection and rapid assessment. Based on the findings, non-medication or non-invasive recommendations are offered to address the symptoms and challenges documented by the patients. In case of significant or concerning records, patients are advised to seek immediate medical attention. Patients may also

present their PROs records on their next followup visits for physician consideration.

2.4. Participants

We selected participants for the current study from the active patients on our PROs program. Patients were enrolled if aged 50-80 yrs, having a confirmed diagnosis of osteoporosis, with or without osteoporotic fracture, reporting symptoms related to osteoporosis such as pain or reduced mobility, having adequate cognitive and communication capacity, and capable of providing informed consent and participating in a 20-40 min face-to-face interview.

Those, who were aged <50 or >80 yrs, had fracture(s) known not to be attributed to osteoporosis such as fracture from a car accident, had a known psychological or physical condition that might affect the results of our current study such as other chronic diseases with unmanaged symptoms, had inadequate cognitive or communication capacity, or were unable to give consent or participate in an interview, were excluded.

The researchers screened for potential participants to the study by reviewing the medical records and PROs management files of patients on the PROs program to determine eligibility. On the initial contact to recruit participants, the researchers visually assessed their mental status and communication capacity.

2.5. Sampling

Purposive sampling was used to enroll participants between January 7, 2024 through February 10, 2024. A researcher accessed the medical records of the current participants on the PROs program to select potential participants and approached them on one of their followup visits.

The researcher first assessed their physical and mental status and communication ability through a casual conversation. If suited, the participants were asked if they were willing to participate in this

study. If yes, the researchers explained the purpose, process, and expected use of the results. If the patient agreed to participate, they were requested to stay for a 20-40 min face-to-face interview after their consultation session. Another researcher might perform the interview if the earlier researcher was unavailable. Interviewers were trained on semi-structured face-to-face interview techniques and familiarized with the interview guide.

2.6. Face-to-face interview

We developed an semi-structured interview guide with open questions (Supplemental Material 1). Interviews were made in a designated room, which was a private quiet environment. Only one participant was interviewed at a time. Any support person or carer was requested to stay outside the interview room. The sampling process continued until data saturation was reached, where two consecutive interviews failed to yield any new analytical information, as determined on consensus of the research team [19].

2.7. Procedure

All researchers were either active care-providers on the PROs program or healthcare professionals of relevant specialties, who had received training in phenomenological research methods and semi-structured interview. Interviews were about 13 min on average (11-19 min), which were recorded using the recorder app on the researcher's smartphone.

The initial inquiry in each interview session was posed as a broad, open-ended question, such as 'Could you tell me your experiences related to your osteoporosis recently?' or 'How has your life been impacted since being diagnosed with osteoporosis?' to encourage participants to freely express themselves.

To delve deeper participants' experiences, probing questions such as "Could you elaborate on that

experience?" or "Can you describe in more detail how that aspect affected you?" were employed to stimulate further reflection and detail, allowing for a comprehensive exploration of the lived experiences of individuals with osteoporosis.

Throughout the interview process, the researcher utilized various techniques to enhance the depth of the conversation and ensure the authenticity of the responses, such as rhetorical questioning to provoke thought, repetition for emphasis and clarification, and reflective responses to demonstrate understanding and empathy towards the participants' experiences.

The researcher took field notes during each interview, capturing crucial non-verbal cues such as changes in the participant's tone of voice, facial expressions, and body gestures, to provide valuable context to the verbal responses. The audio recording of each interview was cataloged and transcribed verbatim by one researcher and reviewed for accuracy by a different researcher in 24 hrs.

To protect participant privacy and confidentiality, all personal identifiers were removed from the transcripts and notes. Participants were numbered as Participant 1, 2, 3... All data, including audio recordings, transcripts, and field notes, were extracted from researchers' smartphone app and stored on two password-protected flash drives. Access to all study materials was strictly limited to members of the research team.

2.8. Rigour and reflexivity

We took strategies to ensure rigor throughout our study, including providing sufficient interview time to gain an in-depth understanding of the phenomenon and to identify and account for any anomalies; cross-verifying our findings, for example, using participants' PROs records; returning all results to participants for validation; involving multiple researchers in the coding process to

mitigate individual biases; and discussing discrepancies in coding to reach a consensus on themes and interpretations. For discrepancies unresolved through discussion, the researcher reached out for participant clarification by phone.

To address reflexivity, we implemented several measures to minimize potential bias. All researchers underwent pre-study training on reflexivity to raise awareness of how personal beliefs and professional backgrounds could influence the study. A reflexivity statement was written as a reminder for the research team, which stresses the importance of maintaining critical self-awareness throughout the process (Supplemental Material 2). We held a main meeting at the start of the study, where researchers reflected on their backgrounds, beliefs, and potential influences on the study and findings. Additionally, reflexivity was a designated discussion point in regular team meetings. We also documented key decisions in the research process.

2.9. Data analysis

We used the Colaizzi's 7-step method for data analysis [18]. First, we immersed in the data by reading all participants' descriptions repeatedly to gain a sense of the overall experience. Key phrases or sentences directly relating to the phenomenon were extracted. Each significant statement was analyzed to derive meanings, which were then grouped into thematic clusters. We then developed an exhaustive description of the phenomenon by integrating all the themes to capture the essence of the participants' lived experiences. The exhaustive description was then synthesized to articulate the fundamental structure of the phenomenon by summarizing the essence of the experience into a concise narrative, which was validated with the participants, ensuring that our analysis accurately reflected their experiences.

2.10. Ethical consideration and informed consent

This study was approved by the Ethics Committee of West China Fourth Hospital, Sichuan University (Approval number 23011). Written informed consents were attained from all participants before interview.

2.11. Patient and public involvement

None.

3. Results

3.1. Demographic and clinical data

Before data saturation was achieved, we approached 14 patients, who agreed to take the interview (100.%). The participants were aged 67.7 years on average (age range, 55-78). Most of them were women (n=10, 71.4%). Their education levels were generally low, with a majority being junior high school or below (n=9, 64.3%). Their symptoms due to osteoporosis varied. The most commonly reported symptom was limited mobility (n=14, 100%), followed by chronic pain (n=10, 71.4%) and weight loss (n=8, 57.1%). Eight participants had one or more fractures, including 4 with multiple fractures (28.6%). All of them had been on the PROs program for an extended period of at least 6 months by the time of interview. (Table 1)

Table 1. Demographic and clinical characteristics (N=14)

Characteristic	**Category**	***n***	**%**
Gender	Female	10	71.4
	Male	4	28.6
Age (years)	50-60	5	35.7
	60-70	5	35.7
	70-80	4	28.6

Education level	Primary school	3	21.4
	Junior high	6	42.9
	Senior high	3	21.4
	College or over	2	14.3
Main symptoms	Chronic pain	10	71.4
	Severe bone pain	5	35.7
	Low back pain	5	35.7
	Weight loss	8	57.1
	Limited mobility	14	100.0
	Stooped posture	3	21.4
Fracture	No fracture	6	42.9
	1 fracture	4	28.6
	⩾2 fractures	4	28.6
Time on PROs (months)	6-8	7	50.0
	9-12	4	28.6
	⩾13	3	21.4

Note: PROs, patient-reported outcomes.

3.2. Themes

We summarized four overarching themes and two sub-themes from our interviews with the participants.

3.2.1. **Overarching theme 1: Varied perceptions of the PROs program**

A prominent theme emerging from our interviews was the significant diversity in participants' attitudes and feelings towards the use of PROs. On one hand, some participants expressed positive response and enthusiasm that the PROs program was extremely beneficial for them:

Quote 1: "I think the PROs program is really great. It helps me record my daily physical condition and pain levels in detail, so I can clearly communicate this to my doctor during visits,

aiding them in adjusting my treatment plan more accurately." (Participant 1)

- Quote 2: "Filling out the PRO questionnaires regularly allows me to better understand the progression of my condition. It helps to improve my symptoms and quality of life. This has been very helpful for managing my condition on my own." (Participant 4)

However, on the other hand, some other participants reported that the PROs program was not particularly helpful:

- Quote 3: "Although I understand that PRO programs are meant to reflect my actual condition, sometimes filling out these forms feels cumbersome, and it seems like they don't immediately improve my symptoms." (Participant 2)

- Quote 4: "I'm not sure if the doctors are really making adjustments based on the PRO data I show them. Sometimes it feels more like a formality, without really having an effect." (Participant 7)

- Quote 4: "Helpful but difficult sometime. I'm not skilled with a (smart) phone. Also, the forms are complicated." (Participant 9)

3.2.2. Overarching theme 2: Enhancing communication and facilitating appointments

An interesting phenomenon highlighted in our interviews was that one of the motivating factors for many patients' continued participation in PRO programs was to use it as an efficient way to communicate their medical conditions with healthcare professionals, especially to help in faster scheduling of appointments with specialists:

- Quote 1: "One reason I keep filling out the PRO forms is because I feel it allows me to frequently and directly let the doctors know about the progress of my condition. It was impossible before without it (the PROs program)." (Participant 3)

- Quote 2: "By submitting the (PROs) forms, I feel that the hospital people can notice changes in my condition more quickly... The waiting time (for appointments) has shortened after reporting symptoms." (Participant 6)

Furthermore, some humorous remarks reflected some of their helpless actions in the real medical environment:

- Quote 3: "Haha, sometimes I wonder if making my symptoms sound a bit more severe could get me an appointment faster. Of course, I know it's not the right thing to do, but it's difficult to get an appointment quickly." (Participant 3)

- Quote 4: "I do believe that by filling out the PRO forms in detail and carefully, at least the doctors know I urgently need their help. To some extent, it seems like 'the more severe the condition, the faster the appointment.'" (Participant 9)

3.2.3. Overarching theme 3: Emotional support through regular interaction

The interview findings revealed that many patients valued the regular one-on-one communication with healthcare professionals. The opportunity to discuss their conditions in detail every one or two weeks had a positive impact on their emotional comfort and psychological support, especially during times of worsening illness:

Sub-theme 1: Building a sense of belonging

In the interviews, two patients mentioned the word "sense of belonging", indicating strong emotional support and fulfillment to some extent.

- Quote 1: "After joining the PRO program, I felt like I was not just a patient but a part of the care team for myself. The feeling of being noticed and understood gave me a strong sense of belonging." (Participant 2)

- Quote 2: "Whenever I submit my condition report, they (followup manager) always respond quickly, making me feel like that someone cares about me and giving me a sense of belonging." (Participant 11)

Sub-theme 2: Providing reassurance and comfort

Three participants emphasized a similar viewpoint, which was that even though the PRO programs might not have immediately changed their actual symptoms, the continuous attention to their condition by healthcare professionals and the professional advice obtained through PRO programs were valuable, which provided them significant inner relief and support:

- Quote 1: "Even though my symptoms are mostly manageable most of the time, knowing that someone is always closely monitoring my condition gives me a sense of security that I am not enduring the pain alone." (Participant 5)

- Quote 2: "Even if the advice is sometimes just simple precautions or lifestyle adjustments, this attention and guidance from professionals reassure me that I am managing my condition correctly, which itself is a great psychological support." (Participant 8)

- Quote 3: "Every time I complete a PRO report and receive responses and suggestions from healthcare professionals, it's like injecting a tranquilizer into my heart, making me realize I'm a scientific method to fight the disease." (Participant 9)

3.2.4. Overarching theme 4: Limitations of remote communication for complex needs

One common feedback from our interviews was that though the participants acknowledged the convenience and attention provided by regular online and telephonic communication modes, they also pointed out the limitations of these methods, primarily regarding the inability to prescribe medications and offer in-depth therapeutic intervention advice:

- Quote 1: "I appreciate being able to communicate regularly with healthcare professionals via phone or online, but when if I need specific medication adjustments, it can't be done (online or by phone). (I) still have to go to see a doctor for prescriptions." (Participant 5)

- Quote 2: "(They give) some basic advice, but for complex conditions or the need to adjust treatments, mere phone or online communication is infeasible." (Participant 6)

- Quote 3: "My disease is complex. Face-to-face examination and in-depth diagnosis by the doctor are really needed. Just relying on a few short sentences over the phone, it's not enough, especially can't prescribe medications by phone." (Participant 9)

- Quote 4: "More convenient than without it (PROs program), but still feels like a building in the air. For example, when my condition worsens at home and there's an urgent need to adjust medication dosages or switch medications, I can't do it through phone even if I report it by communicating with the health professional (on the PROs program). Still have to wait until the next clinic visit, though appointment is indeed faster." (Participant 12)

In summary, participants reported a spectrum of experiences with the PROs program, which reflected both its benefits and challenges. While the program facilitated symptom tracking, enhanced communication, and provided emotional support, they also identified significant barriers, including technological difficulties and the limitations of remote communication in addressing complex medical needs.

4. Discussion

PROs have been increasingly recognized and adopted in managing chronic diseases. These tools provide healthcare professionals with direct insights into patients' subjective experiences,

symptom burdens, and the impact of illness on their daily lives, thereby enriching clinical decision-making with a more holistic view of patient well-being [20]. In the context of osteoporosis, a condition often characterized by silent progression and acute symptomatic episodes, PROs can play a crucial role in identifying subtle changes in patient condition, from monitoring treatment effectiveness to facilitating timely interventions [21]. Our findings suggest that PROs can capture the nuanced experiences of patients with osteoporosis, which helps in tailoring treatment plans to individual needs and potentially enhancing patient engagement and satisfaction, consistent with prior reports on other conditions [22-24].

Our interviews with symptomatic patients with osteoporosis on a PROs program for symptom management and QoL improvement yielded enriching findings about various aspects of PROs adoption in realistic settings. According to Theme 1, patients perceived use of PROs differently, which reflects a critical aspect of patient-centered healthcare, individual variability in response to health interventions [25]. Our findings reveal a spectrum of experiences with PROs, including both potential benefits and challenges.

Positive feedback from participants emphasizes the value of PROs in enhancing doctor-patient communication and self-management of the condition, which resonates with Theme 2 where participants find PROs bridging doctor-patient communication. These patients perceive PROs as a tool that facilitates a more accurate and detailed representation of their health status and also empowers them to take an active role in their care. This aligns with existing literature that suggests PROs can improve the quality of care by providing clinicians with a more comprehensive understanding of patients' experiences, potentially leading to more tailored and effective treatment plans [26,27].

In contrast, the challenges highlighted by other participants point to significant barriers in the implementation and utility of PROs. These include the perceived burden of completing the forms, doubts regarding the clinical integration of PRO data, and accessibility issues, particularly related to technology use. Such concerns are reflective of broader issues in the development and deployment of PROs, where the design, complexity, and integration into clinical workflows can significantly impact their effectiveness and patient engagement, which might echo with past lessons learned in designing and implementation of clinical services [28-30].

The variation in patient perceptions of PROs necessitates a more tailored approach to their implementation and use within clinical settings. Simplification of the PRO tools and making them more user-friendly for patients of varying technological proficiencies may ensure that the data collected using these tools are better encouraged and complied with. To effectively implement PROs in clinical practice, healthcare providers should prioritize tailoring the tools to accommodate the diverse needs and preferences of patients. For example, simplifying the forms, providing clear instructions, and offering technical support can reduce the burden on patients, particularly those with limited technological proficiency.

The effect of PROs to bridge doctor-patient communication is well documented [31,32]. Participants' narratives reveal that PROs serve as a tool for symptom tracking and health reporting as well as significantly an effective communication channel between patients and healthcare providers. As exemplified by Participant 3, the ability to frequently and directly inform doctors about the progression of one's condition was perceived as a novel and empowering aspect of care that was previously unattainable. Healthcare providers can establish structured feedback loops where PROs data are regularly reviewed and discussed with patients. This approach not only

validates the effort patients put into reporting their symptoms but also strengthens the doctor-patient relationship.

Moreover, the participants' comments also shed light on the pragmatic strategies some patients employ to navigate the often fraught and congested pathways to receiving timely medical attention. For instance, Participant 3's humorous yet poignant admission of exaggerating symptoms to expedite appointment scheduling underscores a broader issue of access to care, a challenge that PROs can inadvertently help mitigate by providing a more immediate and transparent depiction of patient needs.

However, it must be noted that the current arrangements within the PROs program to expedite appointment scheduling pose a risk of patients potentially over-reporting their conditions. This unintended consequence highlights a critical area for careful consideration and calibration in the implementation of PRO systems.

While the immediacy and transparency afforded by PROs are invaluable for enhancing communication and streamlining care pathways, they also introduce the possibility of skewed data due to patients, as noted by some participants, possibly exaggerating symptoms to secure faster medical attention. This phenomenon, while understandable from the patient's perspective, especially in the face of long wait times and perceived barriers to accessing care, could lead to inefficiencies and misallocations of healthcare resources as well as misinformed clinical decisions. This raises important ethical and practical questions about how to maintain the integrity and accuracy of patient-reported data while ensuring that the system remains responsive and equitable.

To mitigate such risks, it is imperative that healthcare providers engage in regular validation checks and foster open, trust-based relationships with patients, such as this qualitative

investigation, to encourage honest and accurate reporting. Also, education and communication strategies can emphasize the importance of accurate symptom reporting, highlighting how over- or under-reporting can impact their own care. Healthcare providers should invest in patient education initiatives to improve the accuracy and reliability of PROs data, including training patients to understand the importance of honest reporting and guiding them on how to effectively use the tools.

Addressing these challenges requires a delicate balance between leveraging the benefits of PROs for enhanced patient-centered care and safeguarding against potential pitfalls associated with self-reported health information [33,34]. As the healthcare landscape continues to evolve with greater digitalization, ongoing research and dialogue among clinicians, patients, and policymakers will be crucial in refining PRO programs to serve as effective, efficient, and ethical tools in patient care and health system management.

The interview findings compellingly illustrate the profound emotional support and psychological comfort that regular doctor-patient communication, facilitated through the PROs program, which is consistent with existing reports on use of PROs [35,36]. The consistent and personalized interaction, through weekly chats on followup reporting and calls, serves as a medium for medical consultation as well as a significant source of emotional support. Furthermore, the mentioning of a "sense of belonging" by participants reflects the transformation of the patient role from a passive recipient to an active member of the healthcare team. Participants articulated that beyond management of physical symptoms, the knowledge that their condition was under constant surveillance and the receipt of timely, personalized advice acted as a psychological buffer against the isolation and anxiety that chronic conditions often engender.

These insights reveal that the value of PROs programs extends far beyond their immediate clinical utility. By fostering regular, meaningful communication between patients and healthcare providers, PROs programs contribute significantly to the emotional and psychological well-being of patients, reinforcing the indispensable role of empathy and support in the treatment of chronic conditions such as osteoporosis [37].

Theme about the limitations of remote communication channels such as phone and online platforms in addressing more nuanced and complex medical needs may be an inherent challenge with PROs initiatives. Participant 5's experience showcases a common scenario where the ease of remote communication is appreciated for its regularity and accessibility but is simultaneously constrained by regulatory and practical limitations around prescribing medications, which impedes timely management of the reported condition and necessitates in-person visits.

Similarly, Participants 6 and 9 articulate the challenges faced when complex conditions or treatment adjustments are involved. The intricacies of managing a chronic condition such as osteoporosis often require detailed examinations and in-depth discussions that are difficult, if not infeasible, to replicate through remote interactions. The lack of physical examination and direct patient observation can lead to gaps in clinical assessment and decision-making, potentially affecting the quality of care.

Furthermore, Participant 12's comment represents the frustration experienced by patients when urgent medical needs arise, and the limitations of remote communication become apparent. The scenario described, a patient's condition worsening at home with an immediate need for medication adjustments, illustrates a critical juncture where the PROs program's utility is challenged by the inability to provide real-time, actionable medical interventions.

These reflections emphasize the necessity for a balanced approach to healthcare delivery, one that leverages the advantages of remote communication for regular monitoring and patient engagement while recognizing and addressing its limitations through integrated care models. Such models should seamlessly combine remote and in-person care services, ensuring that patients receive comprehensive, timely, and effective care, particularly for conditions requiring close management and frequent adjustments. Bridging this gap is essential for maximizing the potential of PROs programs in enhancing patient care and outcomes in the management of chronic diseases such as osteoporosis. To address the limitations, healthcare providers may consider hybrid care models combining remote monitoring with in-person visits. For instance, periodic in-person reviews, not necessarily occurring during clinical visits but designated sessions of the PROs program, could complement remote symptom tracking. This can ensure that complex medical needs are better addressed.

Limitations

Two main limitations of our study should be noted. Firstly, our participant selection criteria, which included individuals who had been actively participating in the PROs program for six months or longer, inherently skews our sample towards patients who are potentially more motivated and engaged with their healthcare management. This selection criterion may inadvertently exclude insights from a significant subset of patients who discontinued the PROs program prematurely. Their perspectives remain unexplored and reported in our study and could provide valuable insights into potential shortcomings or challenges of PROs programs such as ours. Secondly, this study focused only on the experiences of patients using PROs and did not

include healthcare providers who interact with and act upon the PRO data, who play a vital role in interpreting PROs, integrating them into clinical decisions, and providing feedback to patients. Including them in future research would allow for a more balanced and comprehensive understanding of how PROs influence patient care and decision-making.

5. Conclusions

PROs programs facilitate symptom tracking, enhance communication, and provide emotional support for patients with osteoporosis. However, limitations such as technological barriers and reliance on remote communication must be addressed. Ethical considerations, including potential over-reporting of symptoms to expedite care, require careful management. Future research should include patients who discontinue participating in the PROs program prematurely and the perspectives of healthcare providers to provide a more balanced, comprehensive understanding.

AI use statement

ChatGPT was used to translate the original Chinese text and refine the English language in the final draft. It was not used in designing or implementing the study, interpreting the findings, or writing of the manuscript draft.

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Contributorship statement

YC and LS conceptualized and designed the study and conducted the interviews; YZ and QZ transcribed the audio recordings; LS verified the transcripts; YC, YZ, QZ, and LS analyzed the data and interpreted the themes; YC drafted the initial manuscript. All authors reviewed and approved the final version for submission and agree to be accountable for all aspects of the work. LS is responsible for the overall content as guarantor.

Competing interests

No competing interest.

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Data sharing statement

The original audio recordings are not to be shared due to institutional privacy protection policy. The PROs questionnaire and data analyzed in the current study are available on reasonable request to the corresponding author.

Ethics approval

This study was approved by the Ethics Committee of West China Fourth Hospital, Sichuan University (Approval number 23011).

Consent to participate

Informed consents were attained from all participants before interview.

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Supplemental Material 1: Semi-structured Interview Guide

Introduction

- Self-introduction
- Briefly explain the study again and the interview
- Emphasize confidentiality and voluntary participation
- Verbally obtain permission for recording the interview
- Allow the participant to ask questions if any

Interview

Start with a general question to break ice:

- Could you tell me your experiences related to your osteoporosis recently? or
- How has your life been impacted since being diagnosed with osteoporosis?

1. General experience

- **Main question**: Could you elaborate on that experience?/Can you describe in more detail how that aspect affected you?
    - Probing questions to relate to the PROs program:
        - What was your motivation to participate in the program in the first place?
        - How were your first impressions of the program?
        - Can you explain that?
        - Why do you think so?

2. Ease of use and accessibility of PROs program

- **Main question**: How easy or difficult is it for you to use the PROs program?
    - Probing questions:
        - Can you walk me through how you typically complete the PROs forms or reports?

- Are there any aspects of the forms that you find particularly clear or confusing?
- Have you experienced any technical challenges, such as difficulty using a phone or computer?

3. Impact on symptom management

- **Main question**: How has the PROs program helped you manage your symptoms?
  - Probing questions:
    - Have you noticed any changes in how you track or understand your symptoms since joining the program?
    - Can you give an example of a time when the program helped you manage a specific symptom or situation?
    - Are there any symptoms or issues that the program does not address well?

4. Communication with healthcare providers

- **Main question**: How has participating in the PROs program affected your communication with your doctor or nurse?
  - Probing questions:
    - Do you feel the program helps you communicate your symptoms more effectively? How?
    - Can you recall a specific instance where the program facilitated better communication or care?
    - Do you think healthcare providers fully understand and act on the information you provide through the program?

5. Emotional and psychological impact

- **Main question**: How has the PROs program affected your emotional well-being or sense of support?

- Probing questions:
    - Does participating in the program make you feel more connected to your healthcare team? Why or why not?
    - Have you found the program to be a source of emotional comfort or support? Can you explain?
    - Are there any emotional challenges you've faced while using the program?

6. Benefits of the program

- **Main question**: What do you think are the main benefits of the PROs program?
    - Probing questions:
        - Are there specific aspects of the program that have positively impacted your quality of life?
        - Do you think the program has made managing your condition easier? Why or why not?
        - Would you recommend the program to others? Why?

7. Challenges and limitations

- **Main question**: Have you faced any challenges or limitations with the PROs program?
    - Probing questions:
        - Are there any parts of the program that you find frustrating or unhelpful?
        - Do you think the program meets all your needs? If not, what is missing?
        - Can you share any specific instances where the program didn't work well for you?

8. Suggestions for improvement

- **Main question**: If you could make changes to the PROs program, what would they be?
    - Probing questions:
        - Are there features you think should be added to the program?

- How could the program be made more convenient or accessible for you?
- Are there any ways the follow-up process could be improved?

9. Long-term use and sustainability

- **Main question**: Do you see yourself continuing to use the PROs program in the future? Why or why not?
  - Probing questions:
    - What keeps you motivated to continue using the program?
    - Are there factors that might make you stop participating in the program?
    - How do you see the program fitting into your long-term care plan?

10. Additional thoughts

- **Main question**: Is there anything else you would like to share about your experiences with the PROs program?
  - Probing questions:
    - Do you feel like we've covered all the important aspects of your experience?
    - Is there anything you feel we should know to better understand the program's impact?

11. End of interview

Thank participant. Offer them a chance to ask questions or share final thoughts.

12. Notes

(1) Ensure the interview setting is private, quiet, and comfortable to help participants feel at ease.

(2) Adjust probing questions based on the participant's responses to encourage depth but don't try to lead the conversation. No need to ask all the questions in the interview guide. However, make sure sufficient meaningful information is obtained.

(3) Pay attention to participant's body language, tone of voice, and facial expressions, noting them for context.

Supplemental Material 2: Reflexivity Statement

English Translation:

Reflexivity Statement

As we embark on this study, it is essential to remain critically aware of our potential influences on the research process and findings. Each of us brings unique cultural, professional, and personal perspectives that could shape how we design the study, collect data, and interpret results.

We recognize that our roles as healthcare professionals specializing in osteoporosis management, along with our shared belief in the value of PROs, may lead us to approach the research with certain assumptions. These include an inherent focus on the benefits of PROs and potential biases in interpreting participants' experiences.

To mitigate these influences, we commit to:

1. Maintaining a reflexive journal to document thoughts, assumptions, and decision-making processes throughout the study.
2. Engaging in open and critical discussions about reflexivity during team meetings to challenge each other's perspectives and interpretations.
3. Actively reflecting on how our professional backgrounds, cultural contexts, and values may shape the questions we ask, the way we interact with participants, and the conclusions we draw.
4. Prioritizing the voices of participants in our analysis and ensuring their experiences guide the findings, rather than our preconceptions.

This statement serves as a constant reminder to critically examine our roles and maintain transparency and rigor in all aspects of the research.

Chinese Original:

反思声明

在开展本研究过程中，保持对我们自身对研究过程和结果潜在影响的批判性意识至关重要。我们每个人都带着独特的文化、专业和个人视角，这可能会影响我们设计研究、收集数据和解释结果的方式。

我们认识到，作为专注于骨质疏松管理的医疗专业人员，以及我们对 PROs 价值的共同信念，可能使我们在研究中带有某些假设。这些假设包括对 PROs 益处的固有关注，以及在解读参与者经历时可能存在的偏见。

为减少这些影响，我们承诺：

1. 在整个研究过程中保持反思性日志，记录思考、假设和决策过程。
2. 在团队会议中进行开放和批判性的反思性讨论，以挑战彼此的观点和解释。
3. 积极反思我们的专业背景、文化环境和价值观如何影响我们提出的问题、与参与者互动的方式以及我们得出的结论。
4. 在分析中优先考虑参与者的声音，确保他们的经历引导研究结果，而非我们的先入之见。

此声明旨在时刻提醒我们，批判性地审视自己的角色，并在研究的各个方面保持透明性和严谨性。