

Patients' adherence to osteoporosis therapy

Exploring the perceptions of postmenopausal women

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ABSTRACT

OBJECTIVE To explore the experiences and perceptions of postmenopausal women regarding strategies to improve adherence to osteoporosis therapy.

DESIGN Qualitative, mixed phenomenologic study using focus groups.

SETTING Family physicians' and specialists' practices and community pharmacies in Hamilton, Ont.

PARTICIPANTS A total of 37 postmenopausal women currently taking at least 1 prescription or over-the-counter medication for osteoporosis.

METHOD Focus groups were conducted using a semistructured interview guide consisting of 10 open-ended questions about patients' perceptions of their osteoporosis medications, their reasons for adherence and non-adherence to therapy, and the effectiveness of strategies they had tried to improve adherence. At least 2 research team members analyzed the data to find primary themes.

MAIN FINDINGS Analysis of data from the 7 focus groups found 6 main factors that influenced adherence to medications: belief in the importance of taking medications for osteoporosis, medication-specific factors, beliefs regarding medications and health, relationships with health care providers, information exchange, and strategies to improve adherence. Strategies that facilitated adherence to medications included having a system for taking medications, using cues or reminders, being well informed about the reasons for taking medications, and having regular follow-up by health care providers for support and monitoring after having been prescribed medications.

CONCLUSION Results of this study provide a better understanding of how patients' perceptions and experiences affect their adherence to osteoporosis medications. Because each patient's reasons for non-adherence might be different, depending on individual beliefs or circumstances, strategies to improve adherence to medications should be individualized accordingly.

EDITOR'S KEY POINTS

- Many factors affect adherence to medication regimens. This study looked at postmenopausal women's perceptions of why they did or did not take their osteoporosis medications.
- Adherence to osteoporosis medications is not as good as it should be; about 50% of women who start taking drug therapy for osteoporosis will discontinue it within 12 months.
- This study found that 6 key factors affected adherence to osteoporosis medications, including patient-health care provider relationships and concerns about adverse effects.
- The study also identified specific strategies for improving adherence. The authors caution that because each patient's reasons for non-adherence might differ, these strategies should be tailored accordingly.

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Fidélité des patients au traitement de l'ostéoporose

Ce qu'en pensent les femmes ménopausées

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RÉSUMÉ

OBJECTIF Examiner les expériences et perceptions des femmes ménopausées concernant les stratégies visant à améliorer la fidélité au traitement de l'ostéoporose.

TYPE D'ÉTUDE Étude phénoménologique mixte qualitative à l'aide de groupes de discussion.

CONTEXTE Cabinets de médecins de famille ou de spécialistes et pharmacies extra-hospitalières d'Hamilton, Ontario.

PARTICIPANTES Un total de 37 femmes ménopausées prenant au moins 1 prescription de médicament en vente libre pour l'ostéoporose.

MÉTHODE On a tenu des discussions en groupes en utilisant un guide d'entrevue semi-structuré comprenant 10 questions ouvertes portant sur la perception qu'ont les patientes de leur médication, les raisons pour lesquelles elles poursuivent ou cessent leur traitement et l'efficacité des stratégies qu'elles avaient utilisées pour améliorer la fidélité. Au moins 2 membres de l'équipe de recherche ont analysé les données pour en extraire les principaux thèmes.

PRINCIPALES OBSERVATIONS L'analyse des données des 7 groupes de discussion a permis de cerner 6 facteurs principaux qui influençaient la fidélité au traitement: la conviction qu'il est important de prendre la médication pour l'ostéoporose, certains facteurs spécifiques aux médicaments, les croyances concernant les médicaments et la santé, les relations avec le personnel soignant, le partage de l'information et les stratégies pour améliorer la fidélité. Les stratégies mentionnées comprennent: avoir un système pour prendre la médication, utiliser des signaux ou mémos de rappel, être bien informée des raisons du traitement, et être régulièrement suivie surveillée et encouragée par l'équipe de soins une fois le traitement amorcé.

CONCLUSION Les résultats de cette étude permettent de mieux comprendre comment les perceptions et expériences des patientes peuvent influencer sur leur fidélité au traitement de l'ostéoporose. Puisque les raisons de cesser le traitement peuvent varier en fonction des circonstances ou des croyances individuelles, les stratégies pour améliorer la fidélité au traitement devraient être adaptées à chaque patiente.

POINTS DE REPÈRE DU RÉDACTEUR

- Plusieurs facteurs influent sur la fidélité à un traitement pharmacologique. Cette étude voulait connaître la perception de femmes ménopausées sur des raisons pour lesquelles elles continuent ou cessent leur médication contre l'ostéoporose.
- La fidélité au traitement pharmacologique de l'ostéoporose est loin d'être idéale; environ 50% des femmes qui commencent un traitement pharmacologique contre l'ostéoporose vont l'interrompre en moins d'un an.
- Cette étude a cerné 6 facteurs qui influent sur la fidélité à la médication anti-ostéoporose, incluant la relation entre patient et personnel soignant et la crainte d'effets indésirables.
- L'étude a aussi cerné des stratégies pour améliorer la fidélité. Les auteurs soulignent toutefois que les raisons pour interrompre le traitement diffèrent d'une patiente à une autre, si bien que les stratégies doivent être adaptées à chaque cas.

Cet article a fait l'objet d'une révision par des pairs.
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Osteoporosis is a serious public health concern in Canada. It currently affects more than 1.4 million Canadians and is a factor in up to 90% of the 30000 hip fractures in Canada each year.¹⁻³ In 1993 in Canada, the cost of treating osteoporosis and its related fractures was estimated at \$1.3 billion.⁴

Osteoporosis medications have demonstrated efficacy for reducing risk of fragility fractures and chronic disability in postmenopausal women; however, these medications must be taken consistently for a minimum of 6 months to be effective.⁴ There is evidence that long-term persistence with osteoporosis medication results in a substantially lower risk of fractures.⁵⁻⁷ Siris et al found a progressive relationship between refills of osteoporosis medications and risk of fracture during a 2-year period. Risk was reduced by 26% among patients who were more than 80% adherent to their medications.⁶

Despite the need for long-term therapy, adherence to osteoporosis medications is not as good as it should be.⁸⁻¹² About three-quarters of the women who start taking drug therapy for osteoporosis are no longer taking it as prescribed within 12 months, and almost 50% have discontinued it completely by this time.¹³ Epidemiologic studies have shown that independent predictors of poor adherence to bisphosphonate therapy include more frequent dosing, adverse upper gastrointestinal (GI) effects, concerns about these medications, and practical difficulties with taking the medications,¹⁴⁻¹⁸ but models adjusted for the significant variables explained only 6% of the variation in adherence.¹⁸ A qualitative study of older women indicated that patients' beliefs about the necessity of treatment, medication safety, cost of treatment, and treatment goals were critical to choice of osteoporosis treatment and adherence to therapy.¹⁹

While research to date has focused mainly on the comparative effectiveness of various strategies to improve adherence, patients' perceptions of and acceptance of these strategies have yet to be fully explored.²⁰⁻²² Patients with chronic diseases, such as osteoporosis, must share

the responsibility for managing their illnesses, a situation that has important implications for how they manage their medications.^{23,24}

The objectives of this study were to explore the factors that influence adherence to medications from the perspective of postmenopausal women prescribed osteoporosis medications and to explore what perceptions these women had about the strategies they had tried to improve adherence. This study builds on previous studies by providing a better understanding of how patients' perceptions and personal experiences influence their responsiveness to various strategies to improve adherence.

METHODS

Study design

A mixed phenomenologic design was used. Focus groups were used to allow participants to build on one another's ideas about factors that affect adherence to medications.²⁵⁻²⁸ Informed consent was obtained from participants, and ethics approval was received from the Hamilton Health Sciences Research Ethics Board.

Participants

Three family physicians, 1 geriatrician, 1 rheumatologist, and 3 community pharmacists recruited participants for 7 focus groups that were held in Hamilton, Ont. Postmenopausal women currently taking at least 1 prescription or over-the-counter medication for osteoporosis were eligible to participate. Women were excluded if they could not communicate in English, were cognitively impaired, or were not able to manage their medications independently. A purposeful sampling strategy was used to recruit participants with specific characteristics that could influence adherence. Women from various age groups, women taking various types of osteoporosis medication for various lengths of time, and women who were perceived by their health care providers to be "non-adherent" with current treatment were sought. Focus groups were conducted until theoretical saturation was reached in the data.²⁸

Data collection and analysis

Focus groups were conducted using a semistructured interview guide consisting of 10 open-ended questions asking patients about their perceptions of their osteoporosis medications, their reasons for adherence and non-adherence to therapy, and the effectiveness of strategies patients had tried to improve adherence. The medication-taking process was used to guide the questions being asked to provide a better understanding of how each of the emerging themes could be mapped onto each stage of the process. Focus groups were recorded and transcribed verbatim. Two facilitators and

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1 recorder attended each focus group and debriefed after each group to record their impressions of the group process and emerging themes.²⁵

Statements that pertained directly to adherence were highlighted, extracted from the transcripts, and grouped into main themes by 2 research team members independently. To minimize bias in data analysis, the researchers bracketed their assumptions. (They had explicitly stated their beliefs and preconceptions about adherence to medication at the onset of the study.²⁹) A code book was developed and updated as each transcript was analyzed to capture emerging themes. A qualitative data retrieval computer program, QSR NVivo, was used to assist with organizing the data.³⁰ Data triangulation was conducted through member checking; summaries of focus group discussions were given to study participants for their feedback to ensure that the researchers had correctly interpreted their experiences.²⁵

FINDINGS

A total of 37 women participated in 7 focus groups between February and June 2005 (Table 1). From focus group discussions, 51 themes were identified and aggregated into 6 main theme clusters: belief in the importance

Table 1. Sociodemographic and clinical characteristics of participants: Median age was 70 years, range 48 to 88 years; median number of years taking osteoporosis medication was 2.0, range 0.02 to 12; N=37.

CHARACTERISTIC	N (%)
Drug plan coverage*	22 (59.5)
History of fracture [†]	13 (35.1)
Family history of osteoporosis	11 (29.7)
Prescribed osteoporosis medication by a specialist	11 (29.7)
Types of osteoporosis medication taken [†]	
• Calcium	30 (81.1)
• Vitamin D	33 (89.2)
• Alendronate	9 (24.3)
• Etidronate	5 (13.5)
• Risedronate	19 (51.4)
• Raloxifene	6 (16.2)
Taking hormone replacement therapy	1 (2.7)
Strategies used to improve adherence	
• Carry a list of medications	12 (32.4)
• Receive telephone reminders from pharmacy	0
• Use medication dosette box	15 (40.5)
• Record medication doses in a book	9 (24.3)

*Provincial drug coverage (Ontario Drug Benefit Plan) or private insurance.

[†]Wrist, spine, hip.

[†]Medications taken by patients at the time of the study. Totals exceed 100% because some patients were taking more than 1 medication.

of taking medication for osteoporosis, medication-specific factors, beliefs regarding medications and health, relationships with health care providers, information exchange, and strategies for improving adherence to medications. The first 5 theme clusters represent either barriers or facilitators to adherence (Table 2). The sixth theme cluster captured participants' experiences with various strategies for improving adherence to therapy.

Belief in importance of taking medications for osteoporosis

Patients were aware of the need to take osteoporosis medications, even though most of them had no symptoms of the disease. Factors that reinforced the need to start osteoporosis medications included being told that their bone mineral density (BMD) was low, feeling a sense of aging, and wanting to avoid the physical consequences of osteoporosis (shrinking, stooping, and fractures). The consequences of osteoporosis were viewed negatively by patients and described as the "pain and inconvenience of a fracture," and "finding myself in bed with broken bones, it just doesn't appeal to me." Avoiding these consequences was a strong motivator for adherence.

Improvement in BMD, not having a fracture, and having a quicker recovery after a fall positively reinforced persistence in taking osteoporosis medications. Even when their BMD did not improve as expected, patients still persisted with medications in the hope that they would prevent osteoporosis from worsening. Although osteoporosis was viewed as a serious condition, some patients believed that lifestyle modifications would be enough to prevent osteoporosis and that medication should be used as a last resort.

Medication-specific factors

Bisphosphonates have strict administration requirements that presented a challenge to adherence; for example, having to be taken on an empty stomach with a full glass of water and requiring patients to remain upright for at least 30 minutes afterward. Some patients were able to rearrange their daily routines to accommodate these requirements, but others would intentionally disregard the administration requirements or forget to take the medication if it did not fit into their schedules. Patients who found rearranging their daily routines difficult preferred the once-weekly dosing option of risedronate and alendronate. Those who had successfully integrated taking medication into their daily routines, however, found it easier to take medication every day rather than once weekly.

Because osteoporosis is usually asymptomatic, patients who had adverse effects from their medications ended up feeling worse rather than better. Gastrointestinal disturbances from taking bisphosphonates were most notable and were described as "horrendous diarrhea" and "wrecking my stomach."

Patients attempted to modify their regimens to avoid or minimize adverse effects. When adverse effects were intolerable, patients tended to stop taking the medications and ask their physicians to prescribe alternative medications. Although certain osteoporosis medications are expensive, cost was not a limiting factor to adherence if patients had insurance coverage for medications. Even patients without insurance expressed a willingness to make sacrifices to pay for the medications because they thought the benefits were worth the cost.

Beliefs regarding medications and health

Some patients were reluctant to take osteoporosis medications because they perceived themselves to have a low tolerance to all medications based on negative experiences they had had in the past. Patients were unwilling to take a medication if they heard that a friend or family member had had a negative experience with the same medication or if they had heard negative publicity about the medication in the media.

Some patients did not like the idea of taking any medications because they viewed medications as

artificial and thought they had unpredictable effects. This was further illustrated by patients wanting to avoid taking too many pills at the same time or too many different types of medications because of concerns about drug interactions. Calcium and vitamin D were perceived as more "natural" than other osteoporosis medications and generally were thought to be safe. For patients who considered themselves healthy, the idea that they needed medication for osteoporosis was disconcerting because this meant labeling themselves as sick or it meant they were taking the easy way out by relying on medication rather than diet and exercise.

When deciding whether they would continue taking their osteoporosis medications, patients considered both the risks and benefits. Fear of breast cancer or cardiovascular events from hormone replacement therapy dominated patients' risk-benefit assessments more than fear of other adverse effects; however, patients were still willing to take hormone replacement therapy if they perceived their personal risk of these serious adverse effects to be low.

Table 2. Quotes from focus group discussions

THEME	QUOTES
Belief in the importance of taking medications for osteoporosis	<p>Has prevented fractures: "I have fallen many, many times. Around my house it's been very icy. You don't believe how many times I fell. I haven't broken one bone yet. And I have osteoporosis [laughing]; you know you read that you break your bones very easily. Not for me!"</p> <p>Could prevent fractures: "I don't understand. If you've got something that's going to improve your health I don't know why anyone would not take it [osteoporosis medication] ... and falling and finding myself in bed with broken bones, it just doesn't appeal to me."</p>
Medication-specific factors	<p>Needing to take medication on an empty stomach: "The thing I don't like about [the medication] is when I get up in the morning, give me that coffee now! And I wait and I'm drinking the water and I'm watching the clock and I'm waiting and I just don't like that."</p> <p>"If I could have taken it [osteoporosis medication] with everything else, fine. But I'd get up and say ah, I forgot, and then I'd think well okay, [I'll take it] 2 hours after the meal and then I'd forget again."</p> <p>"I think it's partially a problem with the digestive tract because it's [osteoporosis medication] hard on your stomach. The reason I was late taking it this week is because I had the flu on Friday when I was supposed to take it and my stomach was so upset so I didn't take it until this morning."</p>
Beliefs regarding medications and health	<p>"I've always been healthy, and I've never had to take medication, so having to take medication is like reaffirming you're getting older and there's a psychological aspect to that."</p> <p>"If something, just even taking a pill helps, why not, right? It's much easier than changing your whole lifestyle [laughing]. It's kind of convenient too; you take a pill and hope for the best."</p> <p>"I would like to come off it and wouldn't like to be on it for a lifetime because even though they start off with glowing recommendations, they often decide later, oh that drug has serious side effects and you shouldn't be on it."</p>
Relationships with health care providers	<p>"He prescribed it and I have a high regard for this specialist and whatever he suggested I was quite willing to comply."</p> <p>"Yes, well I'm sort of accepting the fact now that [physicians] must feel that that's not what they're there for [providing information about medications]."</p>
Information exchange	<p>"Even going to the specialist this week, I only took in a small portion of what he said. So I can't imagine a lay person being able to absorb everything about medication. You don't have the language and you don't have the knowledge, and it's very scary."</p> <p>"I have found when I go to have my prescription filled I ask for it [medication information]. I say I want printouts and it's just a matter of, I feel I'm responsible for my medication too and I ask for a printout."</p>

Relationships with health care providers

Trust in their physicians' knowledge and expertise was a key factor in patients' acceptance of osteoporosis medication. Some patients believed physicians were strong advocates of medication and that they prescribed medications too readily. If patients perceived that their physicians were prescribing medications without careful consideration of their need for these medications, the physicians' credibility was diminished, which could have a negative effect on adherence.

It was important for patients who had problems with their medications to feel comfortable discussing their problems with their physicians to prevent them from discontinuing the medications on their own. Patients expected their physicians to be nonjudgmental when they confided in them about their difficulty with taking medications, and they wanted their physicians to offer suggestions for managing their medications more easily. If physicians were perceived by patients not to be providing sufficient follow-up after prescribing medications, patients felt they were not receiving the support they needed to continue taking their medications.

Information exchange

Reviewing patients' BMD results with them helped them evaluate the status of their osteoporosis, which motivated them to either start or continue taking their medications. Patients said their health care providers did not always give them enough information about medications or gave them information in a format that was difficult to understand. Both physicians and pharmacists were perceived as credible sources of information, but participants thought physicians did not have enough time to adequately explain medications to patients, while pharmacists had time to explain more thoroughly and could fill in any gaps in the information. If patients thought they were not receiving the information they wanted from their health care providers, they said they would seek out information on their own. Conflicting advice on medications from different health care providers made it difficult for patients to know what to believe and was a potential barrier to adherence.

A notable theme was how patients reacted to a recent media focus on the adverse cardiovascular effects of hormone replacement therapy. There was a general feeling that very little is known about the adverse effects of medications or that information on adverse effects might be intentionally withheld from the public. The fear that new information about serious adverse effects of other osteoporosis medications would emerge in the future was a potential barrier to long-term adherence.

Factors influencing adherence and strategies for improving adherence

We hypothesized that each of the themes identified in this study could be linked to a stage in the medication-taking

process: patient requires medication, medication is prescribed, patient decides to have prescription filled, initial and continued adherence to medications (Figure 1). All steps of the process are necessary for patients to realize the full benefit of medication for chronic diseases. At any stage of the process, various factors can influence adherence. The adherence strategies identified in this study were linked to stages in the medication-taking process to help patients and providers recognize where they can use these strategies to improve adherence. Establishing a system or daily routine for taking medications and being well informed about medications were among the most important strategies.

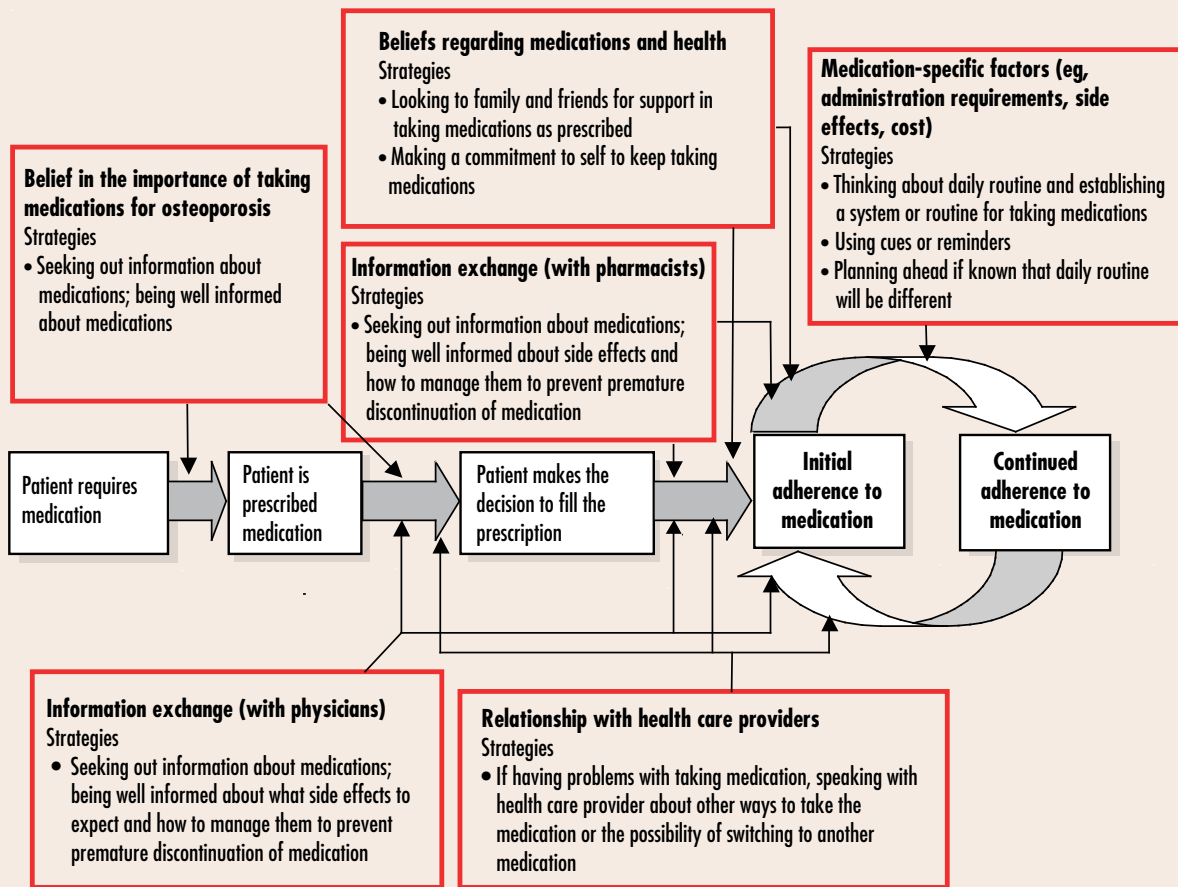
DISCUSSION

The results of this study provide an in-depth understanding of how women's perceptions and experiences facilitated or detracted from adherence to osteoporosis medications. Patients' relationships with their health care providers influenced how they viewed taking medications. A perceived need to avoid the negative consequences of osteoporosis was another key factor facilitating adherence. The challenges of dealing with the strict administration requirements of bisphosphonates and the actual or perceived adverse effects of medications were important barriers to adherence.

Health care providers' willingness to spend time explaining medications to patients and providing regular follow-up motivated patients to continue taking their medications. Health care professionals' monitoring has been demonstrated to increase adherence by 57% among postmenopausal women with osteopenia.²² Patients thought health care providers could provide more in-depth information about the expected effects of medications and more specific instructions on how to take medications. It is well established that knowing more about their medications can empower patients to take a larger role in managing their medications.^{31,32} Because physicians might not always have the time to give patients all the information they need, patients can be directed to their community pharmacists and to societies, such as Osteoporosis Canada or the National Osteoporosis Foundation, for additional information.

Given that osteoporosis is often asymptomatic, it is important for health care providers to educate patients about their personal risk factors for osteoporosis to help them understand the importance of adherence to medications. Knowing their BMD influenced patients to take their medications, as had been found in another study where patients who were informed that their BMD had improved with osteoporosis medication were 92% more likely than those who were not so informed to adhere to therapy.³³ These findings indicate that regular review of BMD results with patients can motivate them to continue taking their medications over the long-term.

Figure 1. Mapping the factors influencing adherence and adherence strategies onto the medication-taking process



A prominent barrier to adherence in this study was the complex and inconvenient administration requirements of oral bisphosphonates. Patients were not always aware of the reasons for these requirements and thus did not always meet them. Further education on the need to take bisphosphonates in the correct way to maximize absorption and minimize upper GI adverse effects would help increase adherence. Patients used strategies, such as waking up earlier in the morning or keeping themselves occupied until it was time to take their medications, to adhere to administration requirements. Most patients found, however, that it was inconvenient to rearrange their daily schedules, which resulted in either intentionally or unintentionally missed doses. Another strategy patients used was to take once-weekly bisphosphonates on a day of the week that would be least likely to disrupt their schedules. Simplifying regimens from once-daily to once-weekly dosing might be important in increasing adherence to bisphosphonates.

Intolerance to osteoporosis medications, especially having adverse upper GI effects with bisphosphonates, detracted from adherence. This difficulty has been

noted in previous studies which found that adverse upper GI effects were the most important reason for early discontinuation of bisphosphonates.¹⁵⁻¹⁷ It was evident that patients were prepared to tolerate adverse effects to a certain extent (eg, taking medications at a time when GI effects would be least disruptive to their daily routines) and if given the proper support, could be persuaded to continue their medications until the adverse effects subsided. Patients who had GI effects found it more acceptable to use once-weekly bisphosphonates so they would only have to deal with the adverse effects once a week rather than every day. Fear of adverse effects arose mainly from a lack of knowledge or from receiving information about adverse effects that was taken out of context. This fear could be alleviated if patients were counseled about what adverse effects to expect when they were first prescribed a medication.

Our medication-taking process shares core concepts with the Medication Adherence Model, which describes the dynamic process of initiating and maintaining adherence to medication in patients with hypertension.³⁴ The


model recognizes that patients' adherence is predicated on the decision to take medications based on perceived need, effectiveness, and safety (purposeful action); that patients establish medication-taking patterns through systems and routines (patterned behaviour); and that patients use information, prompts, and events to re-assess whether they will remain adherent to medications (feedback). The process of weighing the benefits and risks of medications when deciding to initiate or discontinue therapy is similar to that described by Woods et al for postmenopausal women regarding hormone replacement therapy.³⁵

The strategies patients used to adhere to osteoporosis therapy were similar to those patients used to adhere to medications for other chronic conditions, such as hypertension, asthma, and diabetes.³⁶⁻³⁸ An important finding in this study was that patients are becoming more active in seeking information on medications and need support from their health care providers to interpret this information in order to make decisions that affect adherence. Health care providers and family and friends had the greatest influence on patients' decisions to start treatment by helping them weigh the risks and benefits of treatment and by educating them on how to take their medications. Once patients accepted the need for treatment, they devised many of their own strategies for incorporating taking medications into their daily routines. They often used a process of trial and error to find strategies that worked best for them. According to our results, patients' reasons for non-adherence can differ depending on individual beliefs or circumstances, so strategies to improve adherence should be tailored accordingly.

Limitations

Focus group participants were women who reported being mostly adherent to medications so we gathered more in-depth information on facilitators than barriers to adherence. Also, it was difficult for some patients to think of adherence only in relation to their osteoporosis medications, so some of the themes that emerged might have arisen from patients' experiences with non-osteoporosis medications. This study was done through focus groups rather than through individual interviews, which made it difficult to examine the in-depth experiences of each individual participant. The focus groups, however, allowed members to build on one another's contributions. One-third of the participants had had a previous fracture or a family history of osteoporosis, which might have made them more motivated than others in the general population to adhere to osteoporosis medications.¹⁷ Women were excluded from this study if they could not communicate in English, which could have created a cultural bias in responses since non-English speaking cultural groups might have different perceptions of health and medications.

Conclusion

Many factors can detract from or facilitate adherence to osteoporosis medications. The most notable are relationships between patients and their health care providers, administration requirements and concerns about the adverse effects of medications, having systems or routines for taking medications, and being well informed about medications. The results of this study provide a better understanding of how patients' perceptions and experiences can affect their adherence to osteoporosis medications. Several strategies that patients perceived to be useful for improving adherence were identified, but further research is needed on how to tailor strategies to meet patients' individual needs. 

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Contributors

Dr Lau, Dr Papaioannou, and Dr Dolovich conceived and planned the study, assisted with data interpretation, wrote the paper, and approved the final version submitted. **Dr Adachi and Dr Sawka** assisted with data analysis and made suggestions for revisions to the paper. **Ms Burns and Ms Nair** facilitated the focus groups, assisted with data analysis, and made substantive suggestions for revisions to the paper. **Ms Pathak** coordinated patient enrolment and assisted in organizing the focus groups.

Competing interests

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