

Patient-Provider Decisions About Long-Term Therapy

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Presentation Summary

Quality-of-life issues, patient adherence, and effective patient-provider communication play key roles in the success of any long-term therapy, but especially in the prevention or treatment of a condition such as osteoporosis, which is often asymptomatic. Quality of life is a multifaceted concept comprising general well-being and life satisfaction, physical and emotional states, intellectual functioning, and work performance/social functioning. Assessing patients' quality of life at baseline through the use of a questionnaire, interview, and physical examination suggests the manner in which long-term therapy will affect their adherence to therapy and future well-being.

In osteoporosis prevention, a decision-making analysis and bone mineral density (BMD) measurement may enhance patient adherence,

which is particularly challenging with hormone replacement therapy (HRT). Healthcare providers should also consider flexibility in dosing. Two major obstacles to persistence with HRT are uterine bleeding and fear of developing breast cancer. When addressing concerns about the possible link between HRT and breast cancer, the care provider should clarify the meaning of disease incidence, absolute risk, and relative risk data.

A model of effective patient-provider communication used by the osteoporosis prevention program at the Oregon Osteoporosis Center is presented. Using a team approach, the program assesses patients' risk for osteoporosis, recommends individual strategies for preventing bone loss, and provides education and counseling during the first visit and follow-up visits to improve adherence.

The decision to initiate long-term therapy for osteoporosis prevention is based on many factors and often poses difficult choices for the patient and the care provider. As with all therapies, associated risks and benefits must be carefully weighed. For example, hormone replacement therapy (HRT), the standard therapeutic intervention for osteoporosis prevention, carries several additional benefits,¹ including a positive effect on the cardiovascular system and a potential benefit to cognition.² However, HRT is also linked to hazards such as increased risk of endometrial cancer (when given without progesterone) and a possible increase in breast cancer risk.¹

When discussing osteoporosis prevention with a healthy patient, the clinician encounters the challenge of how to make an asymptomatic patient understand the importance of preventive measures. At the core of the problem lies the question: Will therapy designed to improve the patient's future quality of life negatively affect her present quality of life? Because the goal in starting a patient on long-term therapy for osteoporosis prevention is continued therapy, quality-of-life concerns as well as adherence issues and patient-provider communications must be carefully addressed.

Quality-of-Life Issues

The effect of osteoporosis on quality of life is seldom appreciated by healthy women in their early postmenopausal years. Although mortality data indicate that women who use hormonal therapy after menopause live longer,³ data about deaths following hip fractures or findings that relate HRT to prolonged life may not convince the woman in her 50s who fears breast cancer.⁴ In such cases, it is vital to discuss how fractures can diminish quality of life as well as how they relate to mortality. Indeed, care providers need to communicate that lifestyle modifications and medications used to prevent or treat osteoporosis are not only effective but may also improve quality of life.

To determine how therapy will affect a patient's quality of life in the short and long term, the care provider needs to assess this factor at baseline. Quality of life is a multifaceted concept encompassing a general sense of well-being and life satisfaction, physical state, emotional state, intellectual functioning, and work performance/social functioning.⁵⁻⁷ In the clinical setting, quality of life can be assessed by evaluating four components: presence of adverse reactions and physical symptoms, distress associated with those symptoms, emotional status, and life satisfaction.

Adverse reactions and physical symptoms discovered on physical examination may indicate that the medication is producing undesirable responses. For example, if a physical examination revealed that blood pressure increased rather than decreased after starting an antihypertensive agent, the physician would change agents.

Distress associated with symptoms refers to the patients' feedback regarding side effects of their condition and/or medical therapy. This distress can be assessed through a preclinical questionnaire that measures the physical, sexual, somatic, and cognitive aspects of the patient's quality of life. The presence of distress usually depends on the manner in which physicians ask patients about certain symptoms. For example, because of rare reports of esophageal erosion among some patients with alendronate, physicians may pose questions about heartburn only after starting therapy. The patient may report symptoms of esophagitis, and both the care provider and the patient may associate these symptoms with the therapy.

The emotional status of the patient, which can also be assessed with a preclinical questionnaire, consists of the patient's feelings about her medical condition. Measures of emotional status include well-being, vitality, anxiety, depression, and sleep disturbance. A major challenge for the clinician is to present the diagnosis such that the patient does not have a negative emotional reaction.

The life satisfaction component of quality of life is evaluated through the use of a preclinical questionnaire or interview. Assessing life satisfaction calls for measuring the patient's attitude toward the social, personal, marital, and job aspects of her life.

Selecting a general or a disease-specific questionnaire is important because quality-of-life issues may differ between postmenopausal women in general and those women with osteoporosis (Table). Quality-of-life issues for postmenopausal women include hot flushes, vaginal dryness, decreased libido, and fear of the long-term consequences of both estrogen deficiency and estrogen replacement.

For women with osteoporosis, quality-of-life issues include decreased physical function in daily activities, adaptation to the disease (eg, reluctance to continue bicycle riding because of potential falls), living with the fear of fracture, and changes in body image.⁸ This latter concern has been underappreciated by clinicians and may significantly affect the patient's emotional status and participation in social activities. An example of a disease-specific questionnaire for quality-of-life assessment is shown in the Appendix.⁶ The questionnaire was intended for an audience of

researchers rather than for widespread use.

Feedback from these questionnaires can play a pivotal role in the clinical evaluation and selection of appropriate interventions. For example, the questionnaire may uncover an emotional status that contraindicates HRT because the patient fears developing breast cancer. The quality-of-life assessment tool also can readily predict patient adherence.

Patient Adherence

Because the term *compliance* has a negative connotation for many patients, the terms *adherence* or *continuation* may be more appropriate when counseling patients on osteoporosis prevention. By using these more acceptable terms, the care provider can help ensure that therapy is continued.

Several steps to improve adherence can be taken prior to initiating therapy. Sharing a decision-making analysis with the patient and, when appropriate, obtaining laboratory studies to diagnose and predict the occurrence of osteoporosis can be helpful. Several studies have linked increased adherence with patients knowing their bone densitometry results.⁹⁻¹² At the initial intervention as well as during continuation of therapy, the care provider should also recognize the differences among adherence issues faced by women being treated for symptoms of menopause, prevention of osteoporosis, or secondary intervention once the disease has occurred.

There are several decision-making analysis models to assist patients and care providers in deciding whether to begin HRT. One model identifies the patient's specific risks of developing breast cancer, cardiovascular disease, and hip fractures.¹³ If such an analysis shows that the benefits of HRT outweigh the risks, it becomes a powerful tool for promoting patient adherence.

With any long-term therapy such as HRT, the care provider who takes a longitudinal approach and makes adjustments according to the patient's specific

Table. Quality-of-Life Issues for Postmenopausal Women and Women With Osteoporosis

Postmenopausal Women
<ul style="list-style-type: none"> ■ Hot flushes ■ Vaginal dryness ■ Decreased libido ■ Fear of long-term consequences of estrogen deficiency ■ Fear of long-term consequences of estrogen replacement
Women With Osteoporosis
<ul style="list-style-type: none"> ■ Decreased physical function ■ Adaptation to the disease ■ Fear of fracture ■ Change in body image ■ Loss of independence ■ Presence of chronic back pain

needs and biology may also enhance adherence. For example, the 50-year-old woman who begins HRT for relief of menopausal symptoms may decide at age 52 that she wants to stop because she is no longer experiencing hot flashes. The care provider, knowing that the protective effect of estrogen will be lost with discontinuation of therapy, should not insist that she continue with the same regimen. Rather, the provider should work to understand the woman's concerns and either adjust her dosing regimen or switch to another appropriate therapy. Involving the patient in this process and making treatment decisions together may improve patient adherence and satisfaction. Indeed, a study at the New York University Medical Center demonstrated that an explanation of HRT's purpose, risks, and side effects enhanced compliance among postmenopausal women 43 to 62 years old.¹⁴

The need for flexibility in dosing also applies to the use of progestins, because one factor in poor adherence to HRT is progestin intolerance.¹⁵ Many patients are troubled by uterine bleeding, which has been rated by women as the primary factor influencing their decision to discontinue HRT.¹⁶ Other problems sometimes associated with progestins include breast tenderness, fluid retention, and negative mood effects.

Another major obstacle to HRT adherence is the fear of developing breast cancer.¹⁷ Here, the care provider must dispel misinterpretations of epidemiologic statistics. While data indicate that one in nine women who live to age 85 will develop breast cancer, the statistic does not accurately reflect the incidence rates for specific decades of life. With this in mind, the clinician should clarify the meaning of relative risk. For women who decline HRT because of breast cancer fear, or for women with a prior malignancy, newer therapeutic options discussed in the last two articles of this supplement should be considered. These options should expand the clinician's ability to develop patient-specific intervention strategies as well as to as-

sure the patient that her regimen is in accordance with her specific needs.

Several studies have linked increased adherence with patients knowing their bone densitometry results.

Patient-Provider Communication

Effective patient-provider communication is a critical element of successful therapeutic intervention for osteoporosis prevention, regardless of the regimen. The importance of good communication extends beyond the physician-patient relationship to the entire healthcare team and is exemplified by the osteoporosis prevention program at the Oregon Osteoporosis Center. The center uses a team approach to assess patients' risk for osteoporosis, recommend individual strategies for preventing bone loss, and provide education and counseling to enhance adherence to the recommended intervention. This program, however, does not include physician-patient contact at the center. The referring physician retains this responsibility throughout the patient's evaluation at the clinic.

Most of the patients participating in the program are in their early postmenopausal years, and all have been referred to the center by their primary care providers. Reasons for referral to the center vary. While most of the patients referred have a family history of the disease, some have other risk factors, or a combination of them. Other women are referred because of reluctance to begin HRT, and they require BMD testing and counseling on the benefits and risks of therapy. Another group of patients are referred because HRT is contraindicated due to breast cancer.

Visits consist of several components, beginning with bone densitometry. While the bone densitometry results are

being analyzed, a nurse evaluates the patient's clinical risk factors based on a questionnaire and an assessment of daily calcium intake. The nurse then prepares a two-page report that includes a qualitative interpretation of the BMD results as well as specific recommendations for prevention of bone loss. After discussing the report with the patient, the nurse concludes the visit with appropriate education.

Patient education begins with defining osteoporosis, describing the disease process, and discussing its causes. This is an ideal time to clarify misconceptions about osteoporosis and how to prevent it. For example, many patients believe that adequate calcium intake and regular exercise are sufficient to prevent bone loss during the early postmenopausal years.

Patient and family education also includes a description of the various treatment options for osteoporosis prevention, pointing out that more options exist today than several years ago. Medications are thoroughly explained. Their purpose, administration, potential side effects, duration of treatment, and cost are discussed. However, preventive therapy is not prescribed at the center. Counseling regarding calcium intake and weight-bearing exercise is also provided, and educational materials are distributed. The patient is then referred back to her primary care provider for follow-up and, when appropriate, the initiation of preventive therapy.

As a crucial member of the prevention team, the primary care provider receives a formal report of the BMD results, as interpreted by the BMD laboratory's medical director, and a summary of the prevention recommendations. Any therapeutic issues uncovered during the educational sessions, such as patient concerns about specific treatment, are also passed on to the primary care provider.

In follow-up visits to the center, patients are encouraged to continue with the prescribed regimen. Patients are asked about their experiences while on therapy and are encouraged to describe

any obstacles to adherence. Identifying strategies to overcome these obstacles is key to successful long-term disease prevention.

Positive reinforcement also helps the patient continue with treatment. During follow-up visits, the counseling nurse looks for any small gains the patient has made, such as increasing calcium intake or beginning an exercise program.

Building Awareness of Osteoporosis Prevention

Results from a study of the attitudes and beliefs of primary care physicians and gynecologists regarding the prevention and treatment of osteoporosis show that most physicians would recommend HRT, calcium, and exercise for early postmenopausal women. However, for women in their early 60s, only half of the physicians surveyed would provide similar recommendations.¹⁸ These findings underscore the need to make both healthcare providers and the public more aware of bone health and successful approaches to osteoporosis prevention during the premenopausal and postmenopausal years. One example of ways to increase public awareness is the Massachusetts Osteoporosis Awareness Program. Other states may follow in this direction.

Because of similarities between hypertension, hypercholesterolemia, and osteoporosis, lessons learned from the increasing public awareness of cardiovascular disease may be applied to osteoporosis prevention awareness. Hypertension, hypercholesterolemia, and osteoporosis all begin as asymptomatic conditions that require prophylactic therapy to prevent long-term consequences. Treatment of each condition also involves lifestyle changes, including diet and exercise, as an integral part of prevention and treatment. Furthermore, they can each be treated with available medications. Finally, all three disorders have specific diagnostic measures—the office blood pressure measurement for hypertension, serum cholesterol levels for hypercholesterol-

emia, and bone densitometry for osteoporosis.

The history of cardiovascular health awareness shows that even though blood pressure measurements have long been part of a routine office visit, 20 years passed before the public understood the need for normal blood pressure to prevent stroke. Several factors helped build public awareness of hypertension: the education of patients about blood pressure while they were being tested in the office, increased media reports on the hazards of hypertension, the availability of more low-sodium foods in supermarkets, and even the accessibility of blood pressure machines at shopping malls. Public interest in cholesterol lowering increased at a much faster pace. In less than 5 years, supermarkets were well stocked with low-cholesterol foods, and patients routinely asked for cholesterol measurements in their care providers' offices.

What would make the public and healthcare providers more aware of bone health? The availability of calcium-fortified foods and beverages is a start among consumers. Unlike with hypertension and hypercholesterolemia, patients and providers are not accustomed to addressing BMD levels. Therefore, providing better feedback and education on bone densitometry to care providers and patients is another important step. Improvements in BMD reporting have begun in some organizations, such as Harvard Vanguard Medical Associates. At Harvard Vanguard Medical Associates, primary care providers receive computerized BMD reports through a paperless chart system. To make the reports more understandable, the terms "standard deviations from peak and age-adjusted normals" are used instead of "T and Z scores," which can be confusing. Improved comprehension of and familiarity with BMD reports should encourage both primary care providers and patients to take a more active role in osteoporosis prevention.

Conclusion

The decision-making process involving therapy for prevention or treatment of osteoporosis should begin with a baseline assessment of the postmenopausal woman's quality of life through a questionnaire, interview, and physical examination. A decision-making analysis, such as one that identifies a patient's risk of breast cancer, cardiovascular disease, and spine and hip fracture, is also useful in deciding whether to begin therapy and which regimen to use. In addition, baseline BMD measurements may encourage reluctant women to begin and to continue therapy.

Effective and routine patient-provider communication, both before initiation of therapy and during follow-up visits, is also crucial to adherence. Patient counseling helps dispel misconceptions about medications and diseases and addresses potential obstacles to continuation, such as uterine bleeding, fear of developing breast cancer, and fear of weight gain.

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Appendix. Final Questionnaire

Section 1: Physical Function (7 Items). Responses: None; a little; a moderate amount; a lot

- How much physical difficulty do you have pushing or pulling heavy doors?
- How much physical difficulty do you have vacuuming?
- How much physical difficulty do you have lifting something heavy, for example a shopping bag or small child?
- How much difficulty do you have with leisure time activities, such as walking, swimming, bowling, golfing?
- How much physical difficulty do you have shopping for clothes or presents?
- How much physical difficulty do you have preparing meals for special gatherings of family or friends?
- How much physical difficulty do you have visiting relatives or friends who do not live close by?

Section 2: Adaptations (9 Items). Responses: Strongly agree; agree; disagree; strongly disagree

- I need to carefully plan activities so I will not become exhausted.
- I avoid travel because it's too much trouble or too tiring
- I have to avoid activities with a group because I can only do things at my own speed.
- My physical health keeps me from doing community service or other volunteer work.
- It is difficult to plan activities even a few days in advance because I never know what my physical health will be like
- I wear clothes I consider less attractive because that's all that fits
- I wear practical shoes for safety
- I use items, for example, reachers and grabbers, to assist me when I reach for things.
- It is difficult for me to reach up or down, so I keep items more or less at eye level.

Section 3: Fears (6 Items). Responses: No, not at all; A little; A moderate amount; A lot

- Does the fear of falling unless holding on to something affect your life?
- Does the fear of falling and not being able to get up affect your life?
- Does the fear of falling and having a fracture (broken bone) affect your life?
- Does the fear of pain from fractures affect your life?
- Does the fear of future physical limitations due to osteoporosis affect your life?
- Does the fear of osteoporosis because of lack of help affect your life?

Section 4: Osteoporotic Changes (3 Items).

- Have you lost height since the age of 25? If yes, how many inches have you lost?
- Have you noticed a change in your posture, such as a round back? If no, how important is it for you to avoid developing this change in your posture? If yes, how important is it for you to hide this change in your posture?
- Have you had a hip, wrist, or spine fracture since age 45? If yes, were any of these fractures the result of a sudden move or a fall from a standing height or less (such as slipping, stumbling, or falling from bed)?

Section 5: Health and Demographics (7 Items).

- How would you rate your overall health?
- How would you rate your quality of life as regards your health?
- Has anyone in your family (mother, sister, grandmother, aunt) or close friends/relatives had osteoporosis?
- Have you ever had your bone density (a test for osteoporosis) measured?
- Have you ever been told by a doctor that you had osteoporosis?
- How old are you?
- With which ethnic group do you most associate yourself?

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