
Attitudes and Perceptions Associated with Osteoporosis and Its Treatments

Terre Satterfield¹, Stephen M. Johnson¹, Nancy Neil² and Paul Slovic¹

¹Decision Research
1201 Oak Street
Eugene, OR 97401
(541) 485-2400
pslovic@oregon.uoregon.edu

²University of Washington
School of Pharmacy Box 358747
Seattle, WA 98195
(206) 616-1044
njneil@u.washington.edu

August, 1997

Acknowledgements

This study of women and osteoporosis would not have been possible without the assistance of the Novartis Corporation and many individuals. In particular, we would like to thank Jeffrey Schein at Novartis for his support of this research. Dr. Charlie Slemenda at Indiana University freely shared his comprehensive knowledge of osteoporosis with us during the creation of the survey instrument. The enthusiastic assistance of three clinical researchers and health educators helped us identify women as subjects for this study. Thank you, especially, to Dr. Cathy Kessenich at the Maine Center for Osteoporosis Research and Education in Bangor, Ms. Judi Oberdorff at the Osteoporosis Research & Treatment Center in Worcester Massachusetts, and Ms. Roberta Mansfield at the Oregon Osteoporosis Center in Portland. We would also like to thank the University of Maryland Survey Research Center, and our project director there Skip Camp, for their administration of this survey. Finally, we appreciate Janet Douglas and Leisha Mullican's work on the preparation of this document, as well as the support generally of all of our Decision Research colleagues.

Contents

| | | |
|-----|---|----|
| 1.0 | INTRODUCTION | 1 |
| 2.0 | METHODS | 2 |
| 2.1 | Instrument Development and Design | 2 |
| 2.2 | Sampling | 2 |
| 3.0 | RESULTS | 3 |
| 3.1 | Demographics | 3 |
| 3.2 | Perceived Risk | 4 |
| | Perceived Risk Summary | 10 |
| 3.3 | Knowledge/Awareness | 11 |
| | Knowledge/Awareness Summary | 19 |
| 3.4 | Behavior | 20 |
| | Behavior Summary | 22 |
| 3.5 | Drug Treatments | 23 |
| | Drug Treatment Summary | 25 |
| 4.0 | DISCUSSION | 26 |
| | References | 27 |
| | Appendix A: Survey Instrument | |
| | Appendix B: Tables | |

1.0 INTRODUCTION

Osteoporosis—porous bones—is a debilitating illness that affects millions of women and about 10% of elderly men. In the United States alone approximately half of all women over 45 years of age, and 90% of women over 75 are affected by this deterioration of the skeletal structure. Osteoporosis is also the primary cause of bone fractures in post-menopausal women, with an estimated 1.3 million fractures a year (Margolis & Moses, 1992). Osteoporosis-related injuries (such as the ubiquitous hip fracture) are a major cause of hospitalizations and admittances to long-term care facilities; death often follows in relatively short order (“Gallup survey,” 1992). The insidious qualities of the disease, particularly the initial absence of outward manifestations or pain, often mean that its onset is left undetected until injury occurs. Consequently, sufferers who are otherwise unaware of the disease’s presence in their lives may miss important opportunities to intervene through preventive and/or restorative actions.

In this study we attempt to understand lay thinking about the risks of osteoporosis on the part of older women, some of whom have been diagnosed with osteoporosis, some of whom have not. Our central research questions fall into four categories, which can be summarized as follows:

- **Perceived Risk** – Where does osteoporosis fit in the universe of other disease concerns? Do women see themselves as at risk from osteoporosis? Is a diagnosis of osteoporosis dreaded, or feared? Is the disease perceived to be life threatening in and of itself, and how does it compare to other illnesses in this regard?
- **Knowledge/Awareness** – How well do older women understand osteoporosis? Do they recognize factors, be they related to heredity, physiology or behavior, that can affect one’s vulnerability to the disease? What is known by older women about the diagnostic and symptomatic features of osteoporosis? What do these women believe about the ability of calcium supplements to rebuild bone? Do they believe that a woman with osteoporosis should curtail her activities? And have they received written information or counseling about osteoporosis-related issues?
- **Behavior** – Which of the behavioral activities known to affect osteoporosis are actually practiced or, where appropriate, avoided by older women? Is a woman’s level of knowledge about osteoporosis related to her reported behavior?
- **Drug Treatments** – What do older women diagnosed with osteoporosis think and believe about the drug treatments—Miacalcin, Fosamax, and hormone replacement therapies—they have been prescribed? Are these particular drug therapies perceived to be safe, effective, and easy to use?

2.0 METHODS

2.1 Instrument Development and Design

Study subjects were asked to respond in a telephone interview to questions on a variety of osteoporosis-related topics. Two similar survey instruments were used (Appendix A); one instrument was developed specifically for use in a general population of older women, and the other for a population of women who were known to have received a clinical diagnosis of osteoporosis. The two surveys were administered in parallel during March and April of 1997 by the University of Maryland Survey Research Center (raw data were forwarded to Decision Research for analysis).

All survey questions were extensively pretested at Decision Research in a series of personal interviews, focus groups, and computer-aided telephone interviews including women with and without clinically confirmed cases of osteoporosis.

2.2 Sampling

GENERAL SAMPLE

Four hundred (400) women between 60 and 80 years of age were sampled nationwide using random digit-dial technology. The sample frame was current (1990) census tracts identified as having a greater-than-average likelihood of older female residents. Thereafter all women had an equal chance of being selected. Subjects from households with two or more older women were randomly selected using the “next birthday” method. The survey response rate for the general sample was 67%.

Census tract prescreening, while not purely random, is commonly used when rare or elusive populations are the subjects of study. This increases the possibility of connecting with an eligible respondent—in this case older women. This method has been shown to approximate a true random sample in that a true random sample will also draw a disproportionate share of its sample from target census tracts (Genesys Sampling Systems, 1995). Thus, the results of this survey can be generalized to female American residents between the ages of 60 and 80 with a 95% chance that the results represent the opinions, attitudes, and beliefs of this population within a sampling error of $\pm 5\%$.

DIAGNOSED SAMPLE

A second, nonrandom telephone survey was conducted to provide a comparison group of 296 women, all of whom have confirmed diagnoses of osteoporosis. Results from this second survey may or may not be generalizable to all women with osteoporosis; its results should instead be thought of as suggestive.

The names of eligible women with confirmed diagnoses of osteoporosis were extracted from the patient records of three, large osteoporosis clinics. Two of these clinics operate in the northeastern United States, the third on the west coast. Clinic employees identified women between 55 and 85 years of age suffering from osteoporosis.¹ Each patient identified by the clinic was sent a letter describing the study and asking if she would be willing to participate. Participants indicated their willingness to be interviewed by telephone by returning an enclosed postcard.

The “diagnosed sample” was divided into four subgroups based on their treatment status: (1) women not receiving osteoporosis-related drug therapy ($N = 40$); (2) women prescribed hormone replacement therapy (HRT, $N = 58$); (3) women prescribed Fosamax ($N = 84$); and (4) women prescribed Miacalcin ($N = 100$). In many cases women who had been prescribed Fosamax or Miacalcin were also taking HRT; these patients were assigned to either the Fosamax or the Miacalcin subgroup (not the HRT group). While we hoped to recruit equal numbers of women for each treatment group, most women who go to clinics for the treatment of osteoporosis are prescribed some form of drug therapy—thus the relatively smaller size of the “no treatment” group. Miacalcin, in addition, was less commonly prescribed in these clinics than either hormone replacement therapies or Fosamax. Consequently, 53 of the 100 patients using Miacalcin and responding to this survey were recruited via a newspaper advertisement; respondents had to correctly identify the drug’s atypical method of administration (nasal spray). The response rate for the diagnosed sample was 98%.

3.0 RESULTS

3.1 Demographics

The mean respondent age in the general sample was 70 years. About 20.0% lived in the northeastern United States, 30.5% in the Midwest, 35.3% in the south, and the remaining 14.8% in the west. The vast majority (91%) of these women were white, just under 6% were black, and the remaining 3% reported being Asian, American Indian, or another race. Forty-one percent had completed high school (or its equivalent), 25% had some college experience, 14% had college degrees, and about 5% claimed graduate degrees. Seventy-nine percent of this sample provided information about their annual income. Of these, 12.4% had annual incomes below \$10,000,

¹ Expanding the age range beyond the parameters used for the first survey permitted a larger sample frame, and thus facilitated this study. The mean age and standard deviation for the diagnosed sample and the general sample were very similar (see section 3.1).

69.2% had incomes between \$10,000 and \$40,000 annually, and 18.4% had annual incomes above \$40,000. Some 92% of women in the general sample reported having health insurance, and all had heard of osteoporosis.²

Among the 296 women in the diagnosed sample, all were between 55 and 85 years of age (mean = 72 years). Nearly 39% were living in the northeastern U.S. at the time of this survey, with just over 2% in the Midwestern, 16% in the southern and 42% in the western parts of the country. As in the general sample, the vast majority (98.7%) of these women were white; none of the respondents were black and only 1.3% reported being of Asian, American Indian or other race. About 7% of women in the diagnosed sample reported not having a high school diploma (or equivalent). Just over 17% of respondents in this group held college degrees, and nearly 12% had graduate degrees. About 86% of the women in this group provided household income information; of those providing income figures, about 11% reported incomes of \$10,000 or less, 59% reported incomes between \$10,001 and \$40,000, and just under 17% reported incomes greater than \$40,000 per year. Nearly 93% of the women in the diagnosed sample had health insurance and, almost by definition, all had heard of osteoporosis.

3.2 Perceived Risk

RELATIVE RISK OF OSTEOPOROSIS

Risk is a multidimensional term. It can incorporate thoughts about probability, extremity of impact, as well as some degree of salience for that risk item to the individual respondent. Nonetheless, given this survey's wording — "In your opinion, is the average woman aged 60 and over at high risk, moderate risk, or no risk for the following illnesses?" — responses tend to emphasize the perceived likelihood (or probability) that an older woman will contract each condition.³ Mean scores were calculated by assigning a value for each response, where "no risk" equaled 1, and "high risk" equaled 4. Figure 1 below illustrates the average risk score for each of 13 illnesses given by respondents from both the general and the diagnosed samples.

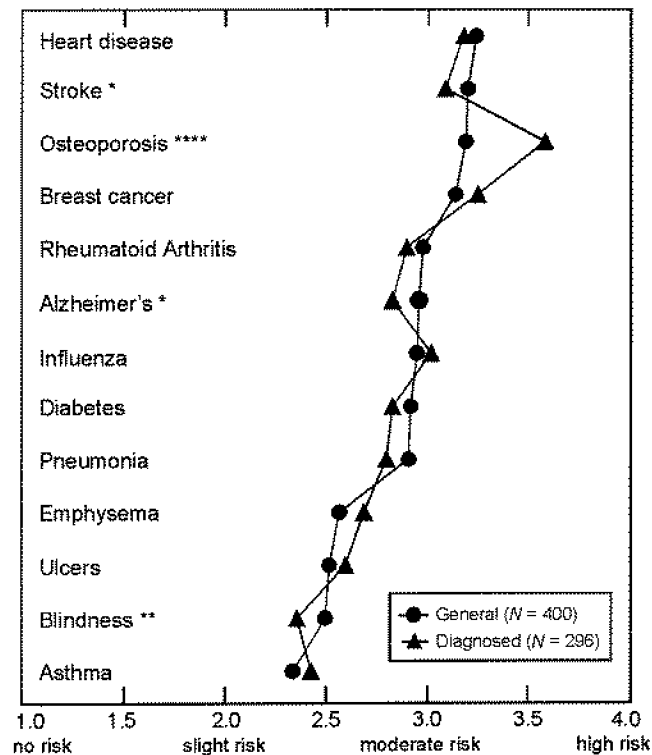
The 13 items in this figure represent a variety of serious illnesses or conditions, consequently no one single item was assigned an average risk score of less than 2.3 (somewhere between a slight and a moderate risk). Heart disease and stroke drew "high risk" evaluations from the largest number of women in the general sample.

² Any random sample of American women will include some women with osteoporosis. In this case, 14.0% of the general sample reported having osteoporosis.

³ This interpretation of risk as lay probability assessments is borne out by the fact that, among women in the general and diagnosed samples who rated older women as at high or moderate risk from osteoporosis, only 10% (general sample) and 16% (diagnosed sample) also viewed osteoporosis as definitely life-threatening.

Figure 1. Perceived risk across illnesses: General and diagnosed sample mean scores.

In your opinion, is the average woman age 60 and over at high risk, moderate risk, slight risk, or no risk from the following illnesses?



*p<.05
 **p<.01
 ***p<.001
 ****p<.0001
 p values indicate statistically significant differences between the general and diagnosed samples.

Interestingly, osteoporosis' average risk score exceeded that for such leading causes of death as breast cancer and pneumonia. This suggests that women are generally aware of the disease's ubiquitous presence as well as the high probability that many women will eventually suffer from osteoporosis to some degree.

The risk-rating pattern offered by diagnosed respondents was very similar to that offered by the general sample. Understandably, osteoporosis represented the only major variation of this pattern. Women with osteoporosis rated it as the illness or condition for which women over 60 are at the highest risk. This should be understood as a "diagnosed" effect. Like women with osteoporosis, study participants who had been diagnosed with heart disease tended to rank heart disease as the number one risk to older women, while those with rheumatoid arthritis tended to give highest risk ratings to rheumatoid arthritis, and so on.

DIMENSIONS OF RISK: DREAD AND FATALITY

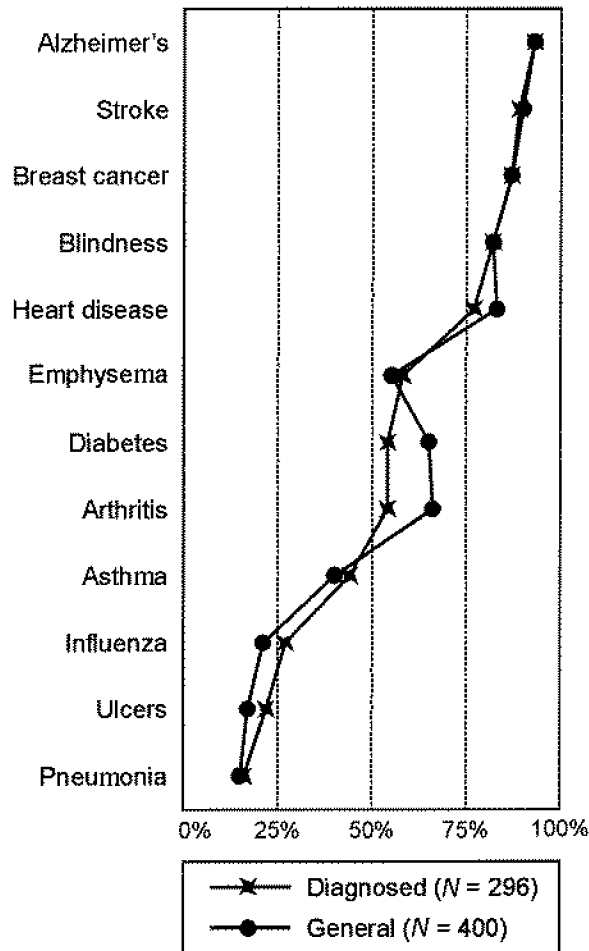
Prior research on the risk construct has demonstrated that dread and fear of fatality are important dimensions of perceived risk (Slovic, 1987). Thus, we asked women in both the general and the diagnosed samples how much they dreaded osteoporosis relative to the 12 other diseases and conditions listed previously (heart disease, stroke, breast cancer, etc.), as well as their judgments about the fatality of each disease.

To make the task manageable in the context of a telephone interview, each respondent was asked to select, from a cluster of four conditions, which condition they dreaded most, second most, and third most. The wording was as follows: “Nobody wants to be ill, but most people dread the idea of having some illnesses more than others. I’m going to read you a list of four illnesses. Which of the following four illnesses do you most dread having? Now which of the remaining would you most dread having? [. . . et cetera]” The same four diseases were then listed again; respondents were asked for similar rankings on perceived fatality (“Which of the following four illnesses do you think is most likely to directly or indirectly lead to death among women over 60?”; then second most likely, and so on). Osteoporosis appeared in each cluster of four diseases; the remaining three diseases in each set were varied from one respondent to the next so that all 12 conditions were rated (relative to osteoporosis) by about an equal number of women.

To represent respondents’ rankings of the dreadedness and fatality of osteoporosis relative to the *full* spectrum of conditions, we scored and combined respondents’ individual choices. Every subject made, in effect, a set of three paired comparisons between osteoporosis and the other three diseases in each set. These three comparisons, one for every subject who completed the task, were used to calculate the percentage of times any one disease was chosen as more dreaded or more fatal than osteoporosis. Each disease was then given an overall ranking based on the percent of respondents judging that disease as more dreaded (or fatal) than osteoporosis. Any disease with a percent score greater than 50 was seen as more dreaded (or fatal) than osteoporosis by at least half of the respondents.

Figure 2 below demonstrates the percent of women in both samples who rated each disease as more dreaded than osteoporosis.

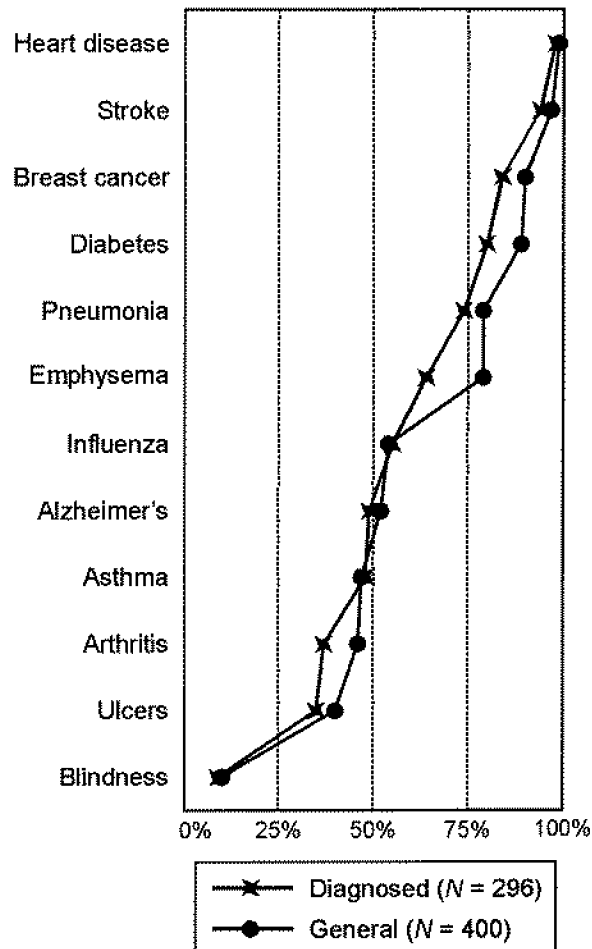
Figure 2. Percent of women rating disease as more *dreaded* than osteoporosis.



Note that eight of the 12 diseases listed were seen as more dreaded than osteoporosis by at least half (50%) of the general- and diagnosed-sample respondents. Some diseases, such as Alzheimer's and stroke, were consistently more dreaded, with 89% or more of respondents in both groups viewing them as more dreaded than osteoporosis. These comparisons revealed that, overall, when dread was considered in relation to osteoporosis, five conditions tended to occupy a "high dread" space: Alzheimer's disease, stroke, breast cancer, heart disease, and blindness. Four conditions (pneumonia, ulcers, influenza and asthma) tended to be less dreaded than osteoporosis, and occupy a lower relative "dread space." Note that women in both samples offered similar dread rankings, with the exceptions of the slightly higher rankings given to arthritis and diabetes by respondents in the general sample.

Fatality rankings offered by respondents in both samples also follow a similar inter-group pattern. Figure 3 below displays diagnosed and general respondents' judgments of fatality for each condition as compared to osteoporosis. Again, a percent score greater than 50% indicates that the condition was judged to be more fatal than osteoporosis by at least half of the respondents.

Figure 3. Percent of women rating disease as more likely to be fatal than osteoporosis.

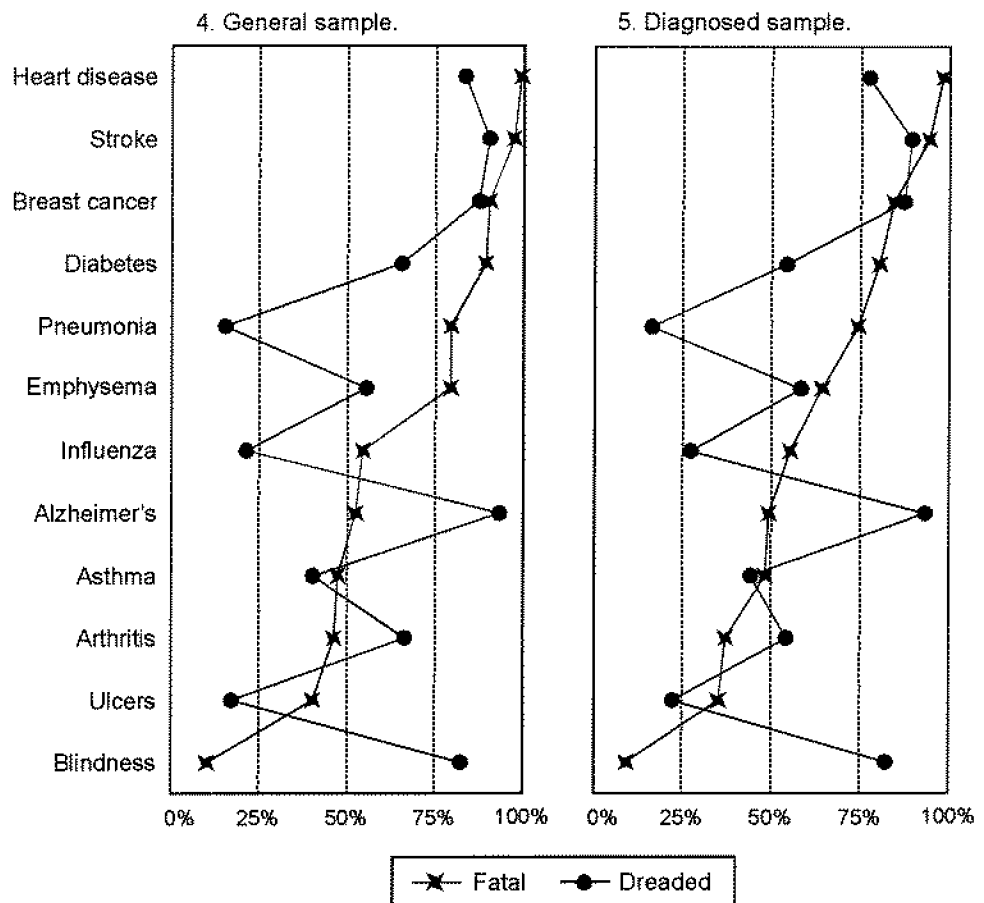


In Figure 3, note that heart disease (the number one killer of women in this age group) was rated as more likely to lead to death than osteoporosis by nearly all respondents in both groups. Other diseases rated consistently as more fatal than osteoporosis—stroke, breast cancer, diabetes, and pneumonia—are all well known and, as corroborated here, widely perceived to be potentially fatal in older women. Only emphysema garnered a ranking score that differed by at least 10% across these two respondent groups. Seventy-nine percent of general-sample respondents versus 64% of diagnosed respondents judged emphysema to be more likely than osteoporosis to lead to death.

The similarity of response across both samples with regard to dread and perceived fatality in part masks the multidimensionality of thinking about disease. Multifaceted thinking about disease is, instead, evidenced by the substan-

tial gap between dread and fatality ratings across specific diseases or conditions. Figures 4 and 5 (below) emphasize these gaps. Figure 4 compares the general sample's dread and fatality ratings while Figure 5 illustrates the differences between dread and fatality ratings for diagnosed respondents.

Figures 4, 5. Percent of women rating disease as more likely to be fatal and more dreaded than osteoporosis.

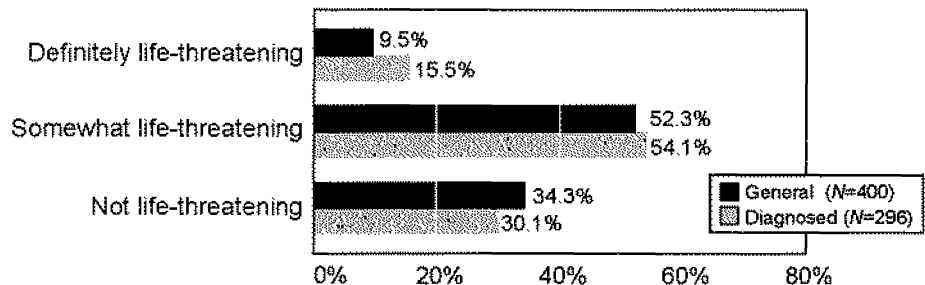


The salient feature of Figures 4 and 5 is the substantial gap within certain diseases and conditions when evaluated on both dreadedness and fatalness. Nine diseases and conditions were viewed quite differently on these two characteristics by general-sample respondents. At the extreme, blindness, a condition that was highly dreaded (82%), was viewed by only a small minority (10%) as likely to lead to death when compared to osteoporosis. Pneumonia, the least dreaded disease (15%), was clearly perceived as fatal (79%) by a majority of general-sample respondents when compared to osteoporosis.

Diagnosed-sample respondents also rated many of these diseases as very different when evaluated, respectively, on fatalness and dreadedness vis-a-vis osteoporosis. Eight diseases (heart disease, diabetes, pneumonia, influenza, Alzheimer's, arthritis, ulcers, and blindness) generated difference scores of at least 12% and as much as 73% when dreadedness and fatalness were compared.

Figure 6. Belief that osteoporosis is life-threatening.

In your opinion, is osteoporosis life threatening?



Women in both groups were also asked if, in their opinion, osteoporosis (in and of itself) is “[definitely, somewhat, or not] life-threatening” (Figure 6).

More than half of all women surveyed viewed osteoporosis as “somewhat life threatening,” while about one-third in each group defined osteoporosis as “not life threatening.” Only a small minority in each group viewed osteoporosis as “definitely life threatening;” however, more women who had been diagnosed with osteoporosis perceived the condition to be life threatening than did women in the general sample (15.5% vs. 9.5%; $p < .01$). It was also true that low-income women (less than \$10,000 income annually) in both samples were more likely to view osteoporosis as “not life-threatening.” Overall, women in this study consistently characterized osteoporosis as a disease that is capable of leading to death, though not definitively fatal.

PERCEIVED RISK SUMMARY

- In general, respondents judged there to be a moderately high risk of osteoporosis for women aged 60 and over, though women who had been diagnosed with the disease tended to rate this risk as much higher than did women not diagnosed with osteoporosis.
- Respondents who had been diagnosed with osteoporosis tended to rank older women’s risk of osteoporosis as far greater than any of 12 other diseases, including heart disease, stroke and breast cancer. Women not diagnosed with osteoporosis tended to rank the risk of osteoporosis similar to that of heart disease, stroke and breast cancer—all of which they characterized as moderately risky.
- More than half of the women in both the general- and diagnosed-samples viewed osteoporosis as “somewhat life threatening,” while about one-third in each group defined osteoporosis as “not life threatening.” Only 15.5% of women in the diagnosed group and 9.5% of women in the general sample indicated that osteoporosis is “definitely life-threatening.”

- Osteoporosis tended to be relatively less dreaded and perceived as less likely to lead to death than were the majority of other diseases.
- Women in both samples perceived some diseases as more or much more dreaded than fatal, while other diseases were recognized as fatal but not seen as particularly dreaded.

3.3 Knowledge/Awareness

Over 90% of respondents in both samples were likely to view osteoporosis as either “well-known” or “somewhat well-known” to women (Figure 7). Diagnosed respondents, however, tended to rate the disease as “somewhat known” (versus “well-known”) more often than did women in the general sample.

In terms of the reversibility of osteoporosis, diagnosed respondents tended to be more confident about the reversibility of the disease than were women in the general sample (Figure 8). Reversibility in this case speaks to the perceived potential for women to “rebuild lost bone density.” Osteoporosis was judged to be “somewhat reversible” or “reversible” by only about half (56.3%) of the women in the general sample, whereas a large majority (85.1%) of the women in the diagnosed sample believed this to be the case.

Figure 7. Belief that osteoporosis is known to women.

In your opinion, is osteoporosis known to women?

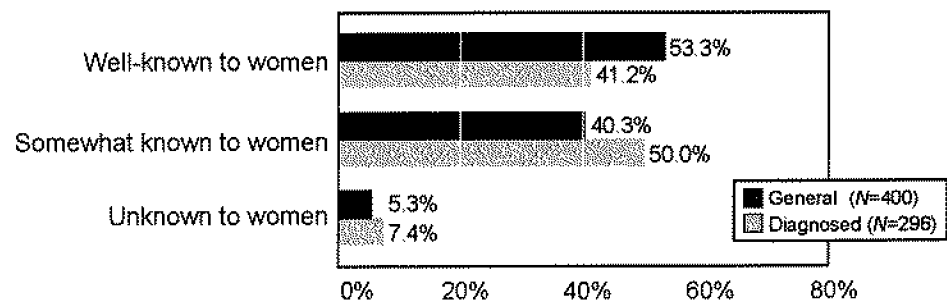
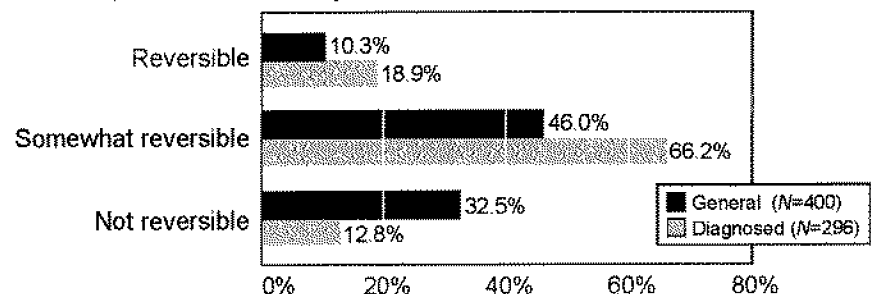


Figure 8. Belief that osteoporosis is reversible.

In your opinion, is osteoporosis reversible?

(By reversible, we mean rebuilding lost bone density.)



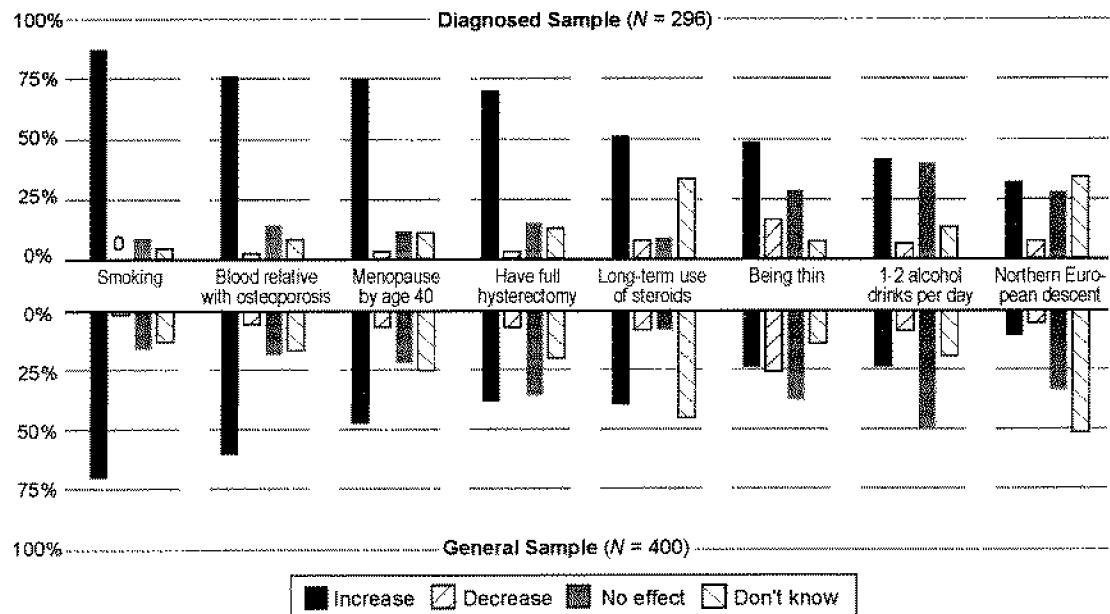
KNOWLEDGE ABOUT FACTORS THAT INCREASE RISK

The likelihood that any woman will suffer the effects of osteoporosis is either mitigated or exacerbated by a variety of behavioral and genetic factors (Margolis & Moses, 1992). Accurate knowledge of these factors should help women understand their relative degree of vulnerability to osteoporosis and, ideally, encourage behavioral precautions to minimize that vulnerability. In order to assess the knowledgeability of our respondents, we asked the women in our two samples a series of 20 general knowledge questions about osteoporosis. Eight of the questions were about genetic factors or behaviors that tend to increase the chance that a woman will develop osteoporosis (e.g., “starting menopause by age 40,” “smoking”); ten of the questions covered factors that tend to decrease a woman’s chance of developing osteoporosis (e.g., “being Black or African-American,” “walking for exercise at least twice a week”); and two of the questions were factors commonly (and erroneously) thought to influence osteoporosis (“swimming for exercise at least twice a week,” “having rheumatoid arthritis”).

Figure 9 illustrates general and diagnosed sample respondents’ awareness of the factors that experts argue increase a woman’s chance of developing osteoporosis. The dark bars in the figure show the percentage of respondents in each sample offering the clinically accepted answer for each item; cross-hatched and light-colored bars indicate the percentage of women who believed that the factor *decreases* or *has no effect* on a woman’s chance of developing osteoporosis, respectively.

Figure 9. Knowledge accuracy: Respondents’ awareness of factors that increase the chance of developing osteoporosis.

*Experts have determined that these items **increase** the chance of developing osteoporosis. Alternately, our two samples perceive the effects accordingly:*



Note that respondents' knowledge varied considerably across items. In terms of overall accuracy, respondents in the general sample were more likely than women in the diagnosed group to offer *incorrect* answers on these items. A majority of women in the general sample selected the correct response on only two items: about 70% identified smoking as a contributor to osteoporosis (a figure which seems remarkably low given that smoking has a highly negative health-related reputation in general), and 60% acknowledged the role of heredity. *Less than half of the women in the general sample correctly identified any other factors as ones that increase a woman's chance of developing osteoporosis.* For three of these factors ("being thin," "1-2 alcohol drinks per day" and "being of northern European descent"), a full three-quarters or more of women in the general sample believed either that the factor decreases or has no effect on a woman's risk of developing osteoporosis, or indicated that they did not know if it has an effect.

Women who had been diagnosed with osteoporosis, in contrast, seemed to have a better overall understanding of factors that increase an individual's vulnerability to the disease, as evidenced by their higher percentage of correct scores on all eight of the items listed. A majority of women in the diagnosed group correctly identified five out of the eight risk-increasing factors, while nearly one-half (48.9%) were correct on a sixth item (being thin). Still, even among those women living with osteoporosis, nearly two-thirds failed to identify the roles of alcohol and northern European ancestry with respect to an individual's chance of developing the disease.

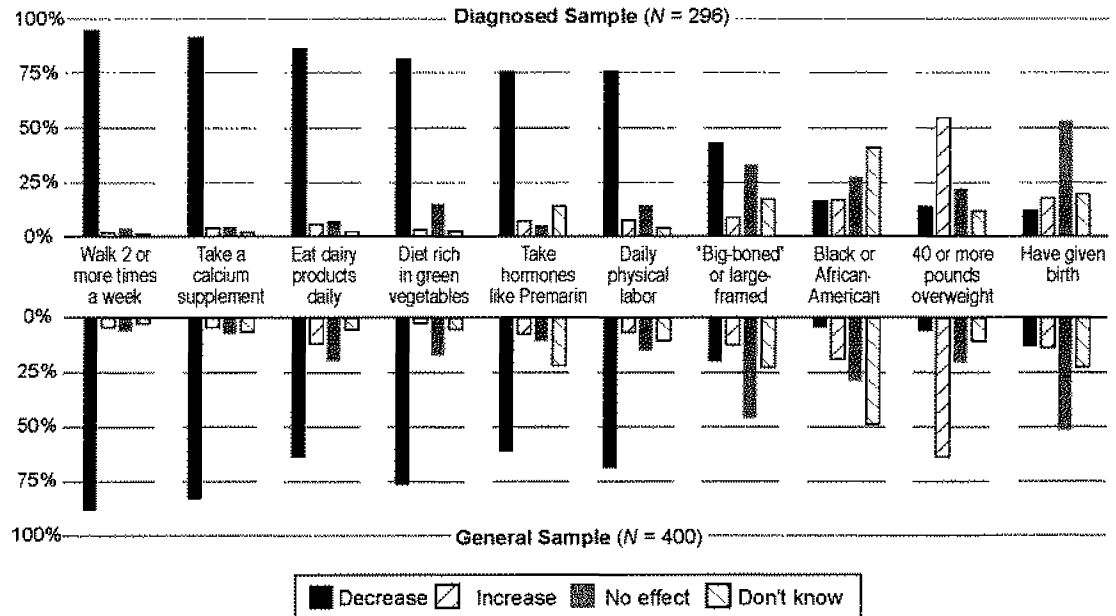
KNOWLEDGE OF FACTORS THAT DECREASE RISK

As indicated in Figure 10 below, a large majority of respondents in both samples correctly identified six of the ten factors—diet, calcium supplements, hormone replacements, and regular exercise such as walking or physical labor—that decrease a woman's chance of developing osteoporosis.

The remaining four items—being big-boned, being Black, being 40 or more pounds overweight, and having given birth—were much less well understood by all respondents as factors that decrease women's chances of developing osteoporosis. Note that of these factors, being Black and being big-boned are genetically driven and thereby outside of an individual's control, and the factor "having given birth," though associated with other decreased health risks such as a decrease in the risk of breast cancer, is not necessarily thought of as related to disease per se. Thus, in general, women in this study were more likely to identify personally controllable factors commonly associated with good health as those that decrease a woman's chance of developing osteoporosis. But women are also vulnerable to factors beyond their control, and an awareness of these factors is important, especially to the extent that such knowledge contributes to extra precautionary effort among those for whom that effort matters most.

Figure 10. Knowledge accuracy: Respondents' awareness of factors that decrease the chance of developing osteoporosis.

Experts have determined that these items **decrease** the chance of developing osteoporosis. Alternately, our two samples perceive the effects accordingly:



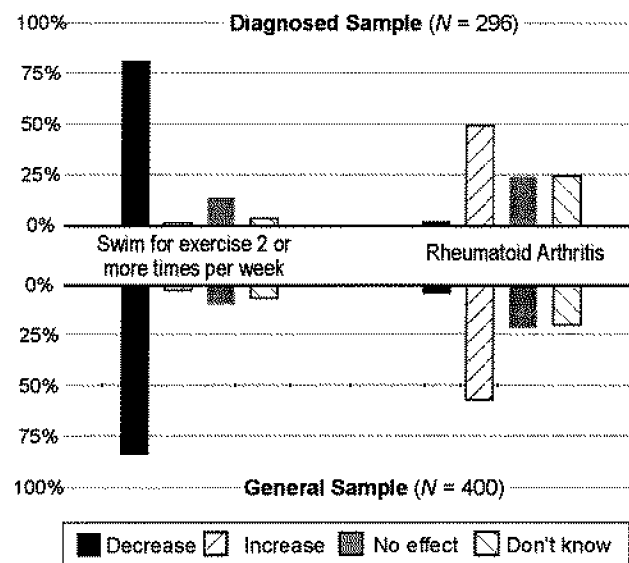
KNOWLEDGE OF FACTORS HAVING NO EFFECT ON RISK

The set of knowledge-related questions included two additional items, swimming and rheumatoid arthritis, neither of which has been identified by experts as having a positive or negative relationship with a woman's risk of developing osteoporosis. However, the women we interviewed in pre-survey focus group contexts commonly thought that swimming at least twice a week would decrease the risk of osteoporosis and that having rheumatoid arthritis was either a predictor or a precursor of osteoporosis. Survey results, shown in Figure 11, mimic those findings.

Over 80% of respondents in both survey samples identified swimming as an activity which decreases a woman's chance of developing osteoporosis. Further, more than 50% of the same respondents identified rheumatoid arthritis as a condition which increases the chances of developing osteoporosis. We hypothesize that respondents understandably (but incorrectly) associate the joint pain of rheumatoid arthritis with true bone disease, in this case osteoporosis. Similarly, since swimming is an activity associated with relieving joint/bone pain and pressure, it may also be associated with osteoporosis-related benefits. It is possible, too, that swimming, by virtue of being a good form of exercise, is perceived as decreasing a woman's overall health risks, including the risk of osteoporosis.

Figure 11. Knowledge accuracy: Respondents' awareness of factors that have no effect on the chance of developing osteoporosis.

*Experts have determined these items have **no effect** on the chance of developing osteoporosis. Alternately, our two samples perceive the effects accordingly:*

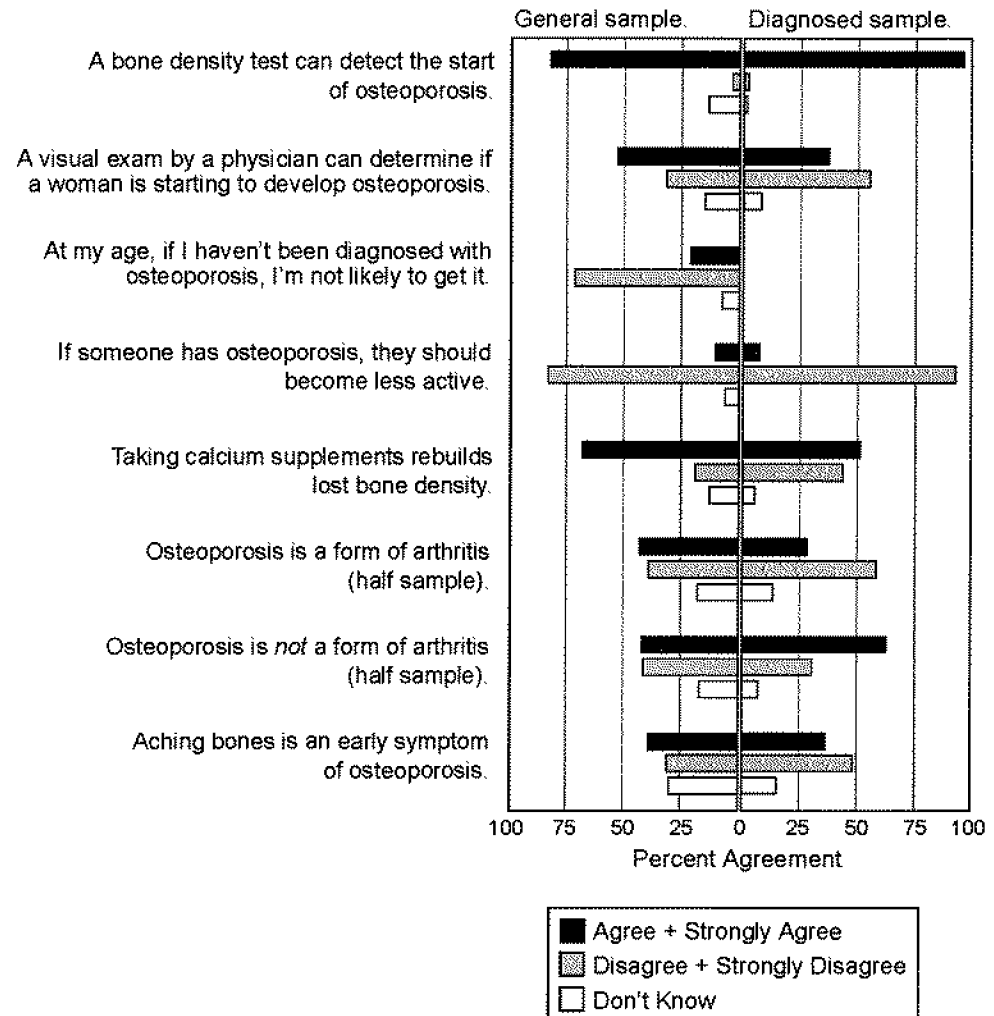


KNOWLEDGE OF SYMPTOMS, DIAGNOSTICS AND OTHER VARIABLES

Eight items related specifically to issues of osteoporosis symptoms, diagnosis, calcium supplementation and level of activity were developed on the basis of women's responses in pre-survey focus groups and other interviews (Figure 12). Each item was offered as a statement to which respondents were asked to either "strongly agree," "agree," "disagree," or "strongly disagree." Results are described below; however, we note here that "strong" responses ("strongly agree" and "strongly disagree"), which generally indicate firm conviction or confidence of position, were relatively rare across all eight of these items for women in both groups (see Appendix 2, table 1).

Again, women diagnosed with osteoporosis were, on the whole, more knowledgeable than were women in the general sample. More than 95% of women diagnosed with osteoporosis agreed that a bone density test can detect the start of osteoporosis, while only about one-third of these women believed that a physician's visual exam could make the diagnosis. In contrast, only 83% of women in the general sample agreed that bone density testing could detect osteoporosis, and more than half believed that a physician's visual assessment could make the determination.

Figure 12. Diagnostic knowledge.



In the case of each of these questions, more than 13% of women in the general sample said they did not know whether bone density testing or a physician's visual exam would be diagnostic. Though they may have been unsure of the method, the ongoing *need* for clinical assessment was evident to women in the general sample: nearly three-quarters of these women disagreed with the statement "At my age, if I haven't already been diagnosed with osteoporosis, I'm not likely to get it."

There was widespread agreement that a woman with osteoporosis should not become less active as a result of her diagnosis. Only about 7% of women diagnosed with osteoporosis agreed that someone with osteoporosis should become less active; the remaining 93% disagreed and no one was unsure. Respondents in the general sample reacted similarly: 10.5% agreed that someone with osteoporosis should become less active, 83.5% disagreed and only about 6% were unsure.

Survey results reflect considerable confusion regarding the benefits of calcium supplementation, especially among diagnosed women. About half of diagnosed women believed that taking calcium supplements would rebuild lost bone density, about 45% disagreed with this statement, and the remaining few didn't know. In comparison, women in the general sample tended to agree with each other, albeit incorrectly: nearly 70% believed that calcium supplementation *could* rebuild lost bone density, while only about 18% disagreed and nearly 13% didn't know.⁴

Respondents were asked directly whether or not they believe osteoporosis to be a form of arthritis. We worded the question two ways in order to avoid "leading" the responses. Half of all women surveyed (general and diagnosed samples) were asked to indicate their level of agreement with the statement "osteoporosis is a form of arthritis," while the other half were presented with the statement "osteoporosis is *not* a form of arthritis." Results show that (1) women's responses overall were not dependent upon the wording of the question, and (2) perceptions varied between the two groups of respondents. Aggregating results across the two forms of the arthritis question indicated that about 30% of the diagnosed sample thought that osteoporosis was a form of arthritis and about 60% did not think this was so. In contrast, about 42% of the general sample thought that osteoporosis was a form of arthritis and 40% thought it was not.

Finally, more than one-third of women in both samples believed "aching bones" to be an early symptom of osteoporosis.

WRITTEN INFORMATION AND COUNSELING

Overall, women who were diagnosed with osteoporosis tended to be more knowledgeable about the condition than were women who had not been diagnosed. This seems reasonable, especially to the extent that health-care professionals take greater care to cover osteoporosis-related topics with women who have been diagnosed with the condition.

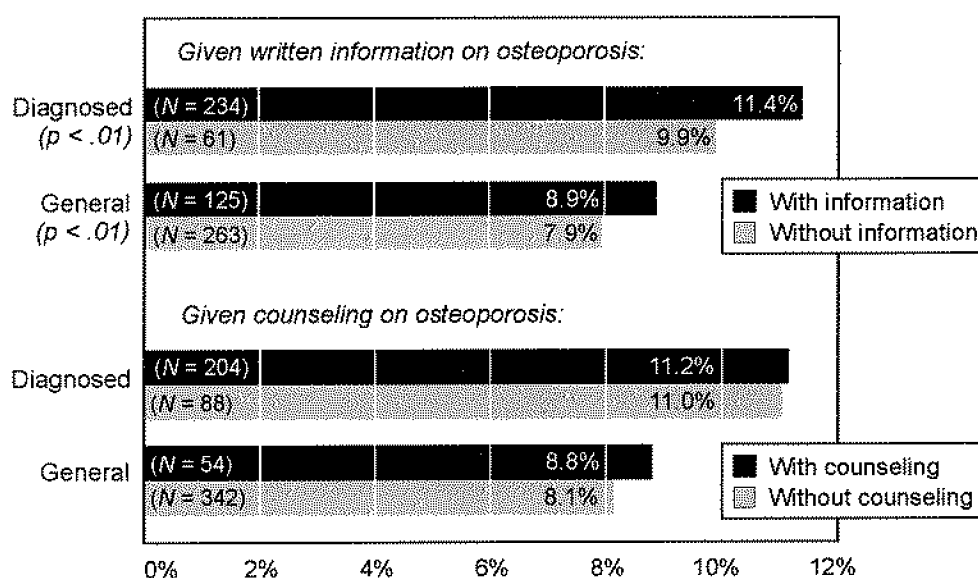
We asked women in both samples, all of whom were age 55 or older, if they had ever received written information, and/or more than 10 minutes of counseling about osteoporosis. Surprisingly few—only about one-third—of women from the general sample recalled receiving written information on osteoporosis, and even fewer (14%) reported having received any counseling on the subject. Perhaps even more surprising, though, was that more than 20% of the women identified as having been prescribed treatment for osteoporosis (or at least seen at an osteoporosis specialty

⁴ The restorative/preventative distinction as it pertains to calcium is admittedly subtle, but it is an important one. Overestimating the powers of calcium has its own consequences.

clinic) did not recall ever having received any written information about the disease, and nearly one-third did not recall ever having received more than 10 minutes of osteoporosis-related counseling.

We were interested in the relationship between the reported receipt of written information or counseling and the accuracy of respondents' osteoporosis-related understanding. Using the knowledge questions outlined in Figures 9 through 11, an index was created to determine if women who indicated receiving either written information or counseling were, on average, any more accurate in their understanding of osteoporosis than their reportedly untutored counterparts (Figure 13).

Figure 13. Knowledge accuracy: Mean scores for general and diagnosed samples across all knowledge items.



The results of this analysis show that mean knowledge scores for respondents who reported receiving written information were, in fact, higher than those of respondents who had not received written information. This was true for women in both the diagnosed and the general samples; however, the difference was most pronounced among women who had been diagnosed with osteoporosis. In contrast, whether a respondent reported having received more than 10 minutes of counseling appeared to have no effect on mean knowledge scores for either sample of women. It would be premature to conclude from these data that counseling is ineffective when compared to written information; however, that written information is beneficial seems evident.

KNOWLEDGE/AWARENESS SUMMARY

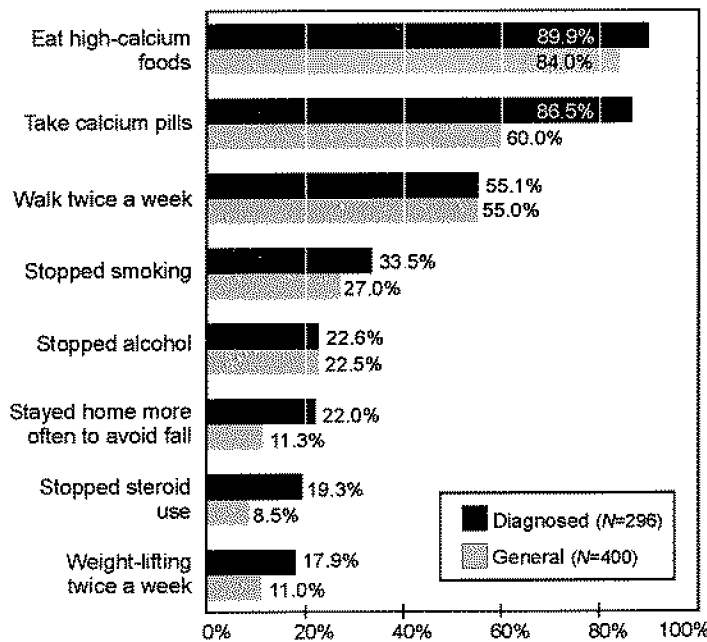
- The majority of older women in both samples regarded osteoporosis as a well-known, reversible condition.
- Women who had been diagnosed with osteoporosis tended to have a better understanding overall of factors that increase an individual's vulnerability to the disease. Less than half of undiagnosed women surveyed correctly identified any factors other than smoking and heredity which can increase an individual's chance of developing osteoporosis.
- A large majority of all respondents correctly identified the potentially mitigating influences of diet, calcium supplements, hormone replacements and regular exercise on the development and/or progression of osteoporosis, though there was considerable confusion about the benefits of calcium supplementation. Further, the vast majority of women did not distinguish between the osteoporosis-related benefits of weight-bearing and non-weight bearing activities. The influences of other factors, such as being big-boned, being Black, being 40 or more pounds overweight, and having given birth, were not well understood by women in both samples.
- Significantly more diagnosed than undiagnosed women agreed that bone density testing could detect the start of osteoporosis. About one-third of women with osteoporosis believed that a physician's visual exam could make the diagnosis, while more than half of undiagnosed women believed this to be true.
- Among women diagnosed with osteoporosis, about 60% correctly indicated that osteoporosis is *not* a form of arthritis, whereas only about 40% of undiagnosed women correctly identified this distinction. More than one-third of women in both groups believed "aching bones" to be an early symptom of osteoporosis.
- Surprisingly few women in the general sample recalled receiving any written information or counseling about osteoporosis. Even more surprising, though, was the finding that 20% or more of women diagnosed with osteoporosis also failed to recall receiving osteoporosis-related information or counseling.

3.4 Behavior

It is the hope of most clinicians, and educators generally, that knowledge engenders action. As we have seen, most of the women participating in this study, whether diagnosed with osteoporosis or not, appeared to recognize conceptually the osteoporosis-related benefits of physical exercise, diet, hormonal and mineral supplements. The next set of questions explored whether this knowledge would be actively expressed in the daily patterns of these women's lives. Participants were questioned about a variety of behaviors, including drug therapies (hormone replacement, Miacalcin and Fosamax) and diet, exercise and smoking habits. We focus first on women's reported diet, exercise and smoking behaviors. Respondents were asked whether or not they regularly engaged in these behaviors and, where appropriate, if they had tried the behavior but stopped. Figure 14 displays these results.

Figure 14. Percent of women who report doing the following osteoporosis-related behaviors.

I am going to read a list of behaviors. Please tell me if you have done any of the following things in the last year.



The percent of women who engage in behaviors known to lessen the effects of osteoporosis or its consequences varies greatly. Regular calcium intake via food and supplements, both of which can be easily integrated into most lifestyles, is widely reported. High calcium foods were reportedly consumed by an overwhelming majority of both diagnosed (89.9%) and general (84.0%) respondents, and a full 86.5% of women diagnosed with osteoporosis reported taking calcium supplements, compared to 60% of women in the general sample. A solid (and equivalent) majority of women in both samples (55%) indicated that they walk regularly for exercise, whereas only 18% (diagnosed) and 11% of general respondents reported practicing weight lifting in the prior year.

Though still a minority, nearly twice as many diagnosed respondents (22%) as general-sample respondents (11.3%) told interviewers that in the past year they had stayed home more often in order to avoid a fall. (Compare this with the only 7% of diagnosed respondents who believed that women with osteoporosis *should* be less active—see Figure 12). This may be a cause for concern, since inactivity remains a greater risk for women with osteoporosis than for women in general.

A promising percentage of all respondents stopped practicing behaviors believed by experts to exacerbate the onset or progression of osteoporosis. Somewhat less than one-half of the women in each group reported ever having smoked (see Appendix 2, table 2); of these, 64.7% of the general sample and 70.7% of the diagnosed sample reported having quit smoking. Similarly, about 60% of both samples indicated some history of alcohol consumption; of these proportions about 40% report having quit or reduced their alcohol consumption. Finally, about 20% of women in the general sample report ever having used steroid drugs like Prednisone; but 43.6% of those who did use these steroids say they have quit. Among diagnosed women, 31% report having used steroids; but 62% of this group say they have stopped using them. Thus, women diagnosed with osteoporosis were nearly 1.5 times more likely to have ceased using steroid drugs than were respondents from the general sample.

RELATIONSHIP BETWEEN KNOWLEDGE AND BEHAVIOR

Knowledge in and of itself, and especially the combination of knowledge and disease onset, may have a powerful effect on corresponding behaviors. Figures 15 and 16 below support this view by showing that women who understand the effects of a particular behavior on osteoporosis may be more likely to act in accordance with that knowledge than are those who do not understand those effects.

For example, Figure 15 shows that general-sample women who understand the benefits of calcium supplements, hormones, and green vegetables were more likely to have reported eating or using these products compared to those with inaccurate knowledge. There was no effect on more popular items like walking or eating dairy products, probably because these items are widely applicable and commonly understood to benefit one's health.

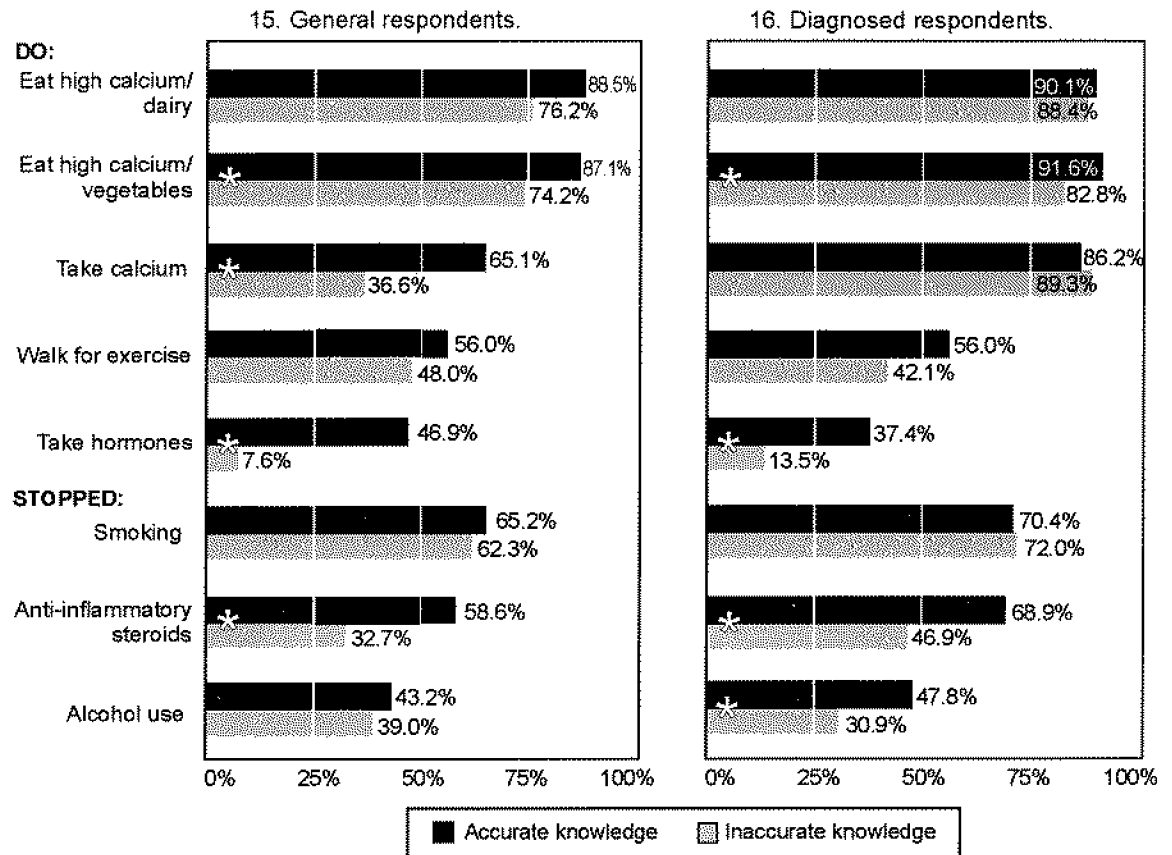
The effect of knowledge on behavior for general-sample women was also significant when considering the cessation of steroid usage. Fifty-nine percent of general-sample women who had used steroids and also correctly understood their impact (negative) on osteoporosis reported cessation of steroid use, compared to only 32.7% of those who were unaware of the effect (negative) of steroids on osteoporosis.

The effects of knowledge on behavior were somewhat more pronounced for women in the diagnosed sample (Figure 16).

Diagnosed women were more likely to eat green vegetables, to take hormones, and to have quit using both alcohol and steroids if they also knew about the effects on osteoporosis of these items. The effects of knowledge on the tendency for diagnosed women to take hormones and to quit using steroids like Prednisone was particularly pronounced. At least 22% more women reported using hormones or quitting steroids when they also understood correctly the effects of these behaviors on the progression of osteoporosis.

Figures 15, 16. Likelihood that accurate knowledge corresponds with pro-active behaviors.

Percent who are both aware of behavior's effect and also act accordingly.

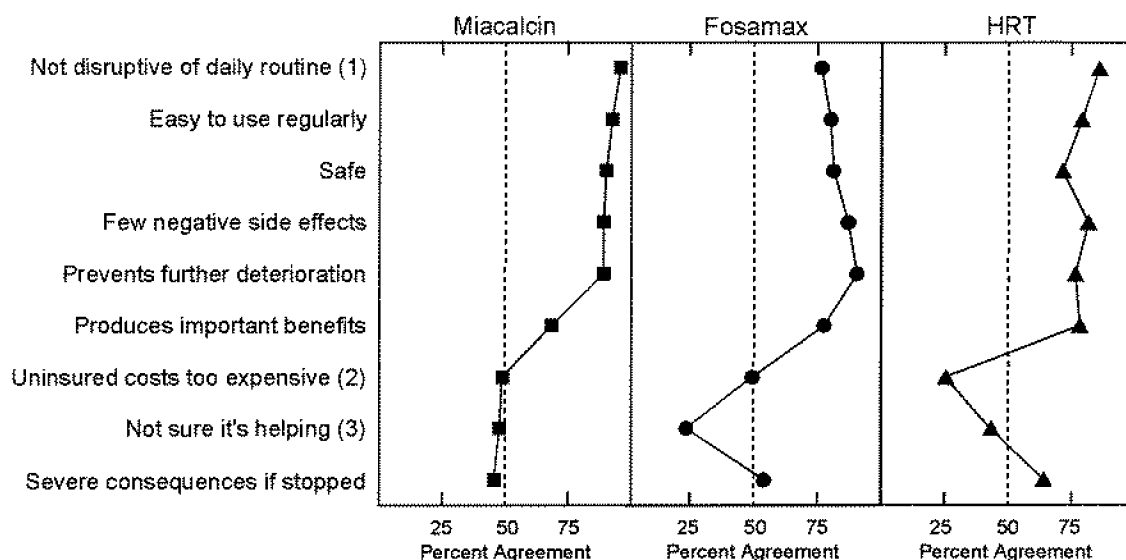


* Items for which a significantly ($p < .05 - p < .0001$) larger percent of women do the behavior when they are also aware of the behavior's effect, as opposed to those who do the behavior regardless of knowledge accuracy.

BEHAVIOR SUMMARY

- Regular calcium intake via food and supplements was widely reported among all older women surveyed.
- A promising percentage of all respondents stopped practicing behaviors, such as smoking and taking steroid-drugs, believed by experts to exacerbate the onset or progression of osteoporosis.
- Data suggest that women who understand the effects of a particular behavior on osteoporosis are more likely to act in accordance with that knowledge than are women who do not understand those effects.

Figure 17. Perceived safety, effectiveness, and ease of using Miacalcin, Fosamax, and hormone replacements (diagnosed women only).



(1) $p < .01$ across all 3 groups; $p < .001$ for the difference between Fosamax/Miacalcin respondents.

(2) $p < .01$ for the differences across all 3 groups.

(3) $p < .03$ across all 3 groups; $p < .02$ for the difference between Fosamax/Miacalcin respondents.

PERCEIVED SAFETY

More of the women prescribed Miacalcin indicated confidence in their therapy's safety (90.2%) compared to women prescribed Fosamax (81.2%) or HRT (71.4%).

Respondents in all three therapeutic groups answered similarly on the subject of side effects: 89% of women in the Miacalcin group, 87% of women in the Fosamax group, and 82% of women prescribed HRT reported "few" negative side effects from their therapies. Finally, women in the Miacalcin group appeared somewhat less worried (46%) about the consequences of stopping Miacalcin than did women in the Fosamax (54%) and HRT (64%) samples.⁵

EASE OF USE

More than 95% of women treated with Miacalcin indicated it was "not disruptive" of their daily routines, compared with only about 86% of women prescribed HRT and 77% of those prescribed Fosamax. Similarly, just over 92% of women in the Miacalcin sample reported that their therapy was "easy to use regularly," compared to only 80% and 79% of women in the Fosamax and HRT samples, respectively.

⁵ The figures represent collapsed "severe" and "moderate" consequences.

Additionally, about half of the women in the Fosamax (49.4%) and Miacalcin (48.9%) groups evaluated the uninsured costs of their drug treatment as “too expensive” versus only 25.2% of the HRT sample. Miacalcin respondents were also more likely (at 41.6%) to disagree that the uninsured costs were too expensive when compared to Fosamax respondents (25.0%). This difference was significant at $p < .01$.

We noted above (section 2.2) that a minority of women take both Miacalcin and HRT or Fosamax and HRT. When those on just Miacalcin were compared to those on both Miacalcin and HRT, no significant differences were found across any of the drug treatment questions discussed in this section. The same was true of Fosamax only versus Fosamax plus HRT respondents.

DRUG TREATMENT SUMMARY

- Respondents in this study were generally positive about their respective drug-treatment programs. A solid majority of all respondents in these three treatment groups, and particularly women treated with Miacalcin, indicated being satisfied with the efficacy, safety and ease of use of their drug treatments.
- Women in the HRT group tended to be somewhat more worried than women in either the Miacalcin or Fosamax groups about the safety and side effects associated with their therapy, but those concerned here were still a minority.
- A majority of all diagnosed respondents acknowledge the benefits of their respective therapies. Fosamax respondents were generally more confident about these benefits than were Miacalcin users. Women taking HRT were somewhat less confident than Fosamax and Miacalcin users about their therapy’s preventative powers and less certain (when compared to Fosamax only) about its “helping” effect. At the same time, HRT respondents were more likely than other respondents to agree that their therapy “produces important benefits” and to anticipate negative consequences if asked about cessation of use.

4.0 DISCUSSION

Compared to the many possible conditions that can afflict older women, osteoporosis tends to be neither dreaded nor perceived as particularly fatal, and thus may pose a difficult problem for medical professionals eager to instill precautionary attention. That is, osteoporosis fails to capture this public's imagination, however grimly, along these two essential dimensions (dread and fatality). Presurvey interviews and focus group findings revealed that women tended to emphasize fatality if and only if death was viewed as sudden, unexpected and/or thought to be especially painful. Dread, alternately, was inspired by some fatal conditions but more importantly by conditions that threatened the capacity for mental and physical independence (losing one's mental faculties was viewed as especially abhorrent). Disease-related events that imposed harsh burdens on family members and loved ones tended to be among the most dreaded.

These findings may help explain the difficulty many practitioners experience when attempting to emphasize the risks of osteoporosis. It is possible that while older women in general understand that they are likely to get osteoporosis—a condition which is perceived to be at least somewhat life-threatening—they are not as well aware of the potential for osteoporosis to impact their physical independence and the need for help from family members and loved ones as a result. Thus, elevated awareness about the impacts of osteoporosis may rest upon women correctly appreciating its long-term implications.

The finding that a large portion of the women diagnosed with osteoporosis demonstrate an awareness of their condition and the factors that contribute to it is certainly positive from a public health point of view. There is also evidence to suggest that women's awareness of osteoporosis-related issues may have a strong effect on corresponding behaviors such as the reduction or elimination of alcohol and/or steroid-drug use. Further, women in this survey who had been diagnosed with osteoporosis tended to be optimistic about the ability of treatment to arrest or reverse progression of the disease.

The clear knowledge gap between undiagnosed older American women and their diagnosed counterparts with respect to osteoporosis is worthy of attention. Far too many older American women, as indicated by these findings, remain unaware of the factors that influence osteoporosis and, as a result, may be less likely to take effective action to control the disease before injury occurs. Further, to the extent that older women are not aware that effective prevention and treatment alternatives for osteoporosis exist, they may be less likely to characterize osteoporosis as a condition to which they *should* attend.

References

Gallup survey finds women underestimate severity, consequences of osteoporosis. (1992, November/December). *Menopause Management*, 1(3), 27.

Genesys Sampling Systems. (1995). *Genesys methodological note: Hispanic sampling alternatives*. Fort Washington, PA: author.

Margolis, S., and Moses, H. (Eds). (1992). *The Johns Hopkins medical handbook: The 100 major medical disorders of people over the age of 50*. New York: Rebus, Inc.

Slovic, P. (1987). Perception of risk. *Science*, 236, 280-285.

Appendix A: Survey Instrument

Appendix B: Tables

Table 1. Diagnostic Knowledge.

| | | Strongly Agree | Agree | Disagree | Strongly Disagree | Don't Know |
|---|------------|----------------|-------|----------|-------------------|------------|
| A bone density test can detect the start of osteoporosis. | Diagnosed: | 31.1% | 65.5% | 1.0% | 1.% | 1.4% |
| | General: | 20.5% | 62.8% | 2.8% | 0.5% | 13.5% |
| A visual exam by a physician can determine if a woman is starting to develop osteoporosis. | Diagnosed: | 8.1% | 29.1% | 42.2% | 12.8% | 7.8% |
| | General: | 8.3% | 45.0% | 27.8% | 4.0% | 15.0% |
| At my age, if I haven't already been diagnosed with osteoporosis, I'm not likely to get it. | Diagnosed: | 0% | 0% | 0% | 0% | 0% |
| | General: | 4.3% | 16.8% | 64.5% | 7.3% | 7.3% |
| If someone has osteoporosis, they should become less active. | Diagnosed: | 1.4% | 5.7% | 72.3% | 20.6% | 0.0% |
| | General: | 1.0% | 9.5% | 67.5% | 16.0% | 6.0% |
| Taking calcium supplements rebuilds lost bone density. | Diagnosed: | 6.8% | 44.6% | 39.9% | 3.7% | 5.1% |
| | General: | 6.8% | 61.8% | 17.5% | 1.3% | 12.8% |
| Osteoporosis is a form of arthritis (half sample). | Diagnosed: | 3.0% | 25.2% | 53.3% | 5.2% | 13.3% |
| | General: | 4.3% | 38.8% | 34.0% | 5.3% | 17.7% |
| Osteoporosis is not a form of arthritis (half sample). | Diagnosed: | 6.2% | 56.5% | 26.7% | 3.7% | 6.8% |
| | General: | 5.2% | 36.7% | 36.1% | 5.2% | 16.8% |
| Aching bones is an early sign of osteoporosis. | Diagnosed: | 6.4% | 30.1% | 43.6% | 4.7% | 15.2% |
| | General: | 3.8% | 35.3% | 29.0% | 2.0% | 30.0% |

Table 2. Osteoporosis-related Behaviors.

I am going to read you a list of behaviors. Please tell me if you have been doing any of the following behaviors.

| No. | Question | | Yes | No | Tried but Quit | |
|-----|--|------------|-------|-------|-----------------------|-----------------|
| D1 | Taking calcium supplements daily? | Diagnosed: | 86.5% | 10.8% | 2.4% | |
| | | General: | 60.0% | 37.8% | 2.0% | |
| D2 | Taking hormones like Premarin or Estrace daily? | Diagnosed: | 31.4% | 59.1% | 8.8% | |
| | | General: | 31.5% | 65.8% | 2.8% | |
| D3 | Staying home more often to avoid a possible fall or injury? | Diagnosed: | 22.0% | 77.4% | 0.3% | |
| | | General: | 11.3% | 88.5% | 0.0% | |
| D4 | Weight-lifting two or more times a week? | Diagnosed: | 17.9% | 79.7% | 2.0% | |
| | | General: | 11.0% | 88.8% | 0.0% | |
| D5 | Vigorous walking for exercise at least twice a week? | Diagnosed: | 55.1% | 39.5% | 4.7% | |
| | | General: | 55.0% | 43.0% | 2.0% | |
| D6 | Taking Miacalcin nasal spray? (Calcitonin) | Diagnosed: | 78.1% | 18.4% | 2.6% | |
| | | General: | n/a | n/a | n/a | |
| D7 | Taking Fosamax pills? (Alendronate) | Diagnosed: | 73.5% | 13.3% | 13.3% | |
| | | General: | n/a | n/a | n/a | |
| D8 | Eating foods high in calcium at least 5 times a week? (dairy products, green vegetables) | Diagnosed: | 89.9% | 8.5% | 1.0% | |
| | | General: | 84.0% | 14.0% | 1.0% | |
| D9 | Swimming for exercise at least twice a week? | Diagnosed: | 20.6% | 74.3% | 5.1% | |
| | | General: | 11.5% | 87.3% | 1.3% | |
| | | | | | Tried but Couldn't | Never Did It |
| D10 | Stopped or reduced long term use of steroid drugs like Prednisone? | Diagnosed: | 19.3% | 11.5% | 0.0% | 68.6% |
| | | General: | 8.5% | 11.0% | 0.3% | 79.8% |
| D11 | Stopped or reduced drinking alcohol? | Diagnosed: | 22.6% | 36.8% | 0.7% | 39.5% |
| | | General: | 22.5% | 34.0% | 0.0% | 43.5% |
| D12 | Stopped or reduced smoking? | Diagnosed: | 33.5% | 12.5% | 1.4% | 52.7% |
| | | General: | 27.0% | 12.3% | 2.5% | 58.0% |

Diagnosed: $N = 296$

General: $N = 400$