Chapter 5: Key Messages

- Bone diseases have a major impact on the population as a whole and especially on affected individuals and their families. Although some bone diseases lead directly to pain and deformity, bone disease often is a "silent" disorder until it causes fractures.
- The 1.5 million osteoporotic fractures in the United States each year lead to more than half a million hospitalizations, over 800,000 emergency room encounters, more than 2,600,000 physician office visits, and the placement of nearly 180,000 individuals into nursing homes. Hip fractures are by far the most devastating type of fracture, accounting for about 300,000 hospitalizations each year.
- Caring for these fractures is expensive. Studies show that annual direct care expenditures for osteoporotic fractures range from $12 to $18 billion per year in 2002 dollars. Indirect costs (e.g., lost productivity for patients and caregivers) likely add billions of dollars to this figure. These costs could double or triple in the coming decades.
- From an individual's perspective, bone disease has a devastating impact on patients and their families. While few die directly from bone disease, for many individuals a fracture can lead to a downward spiral in physical and mental health that for some ultimately results in death. In fact, hip fractures are associated with a significantly increased risk of death, especially during the first year after the fracture.
- Bone diseases dramatically affect functional status. Many individuals who suffer fractures experience significant pain and height loss, and may lose the ability to dress themselves, stand up, and walk. These individuals are also at risk of complications such as pressure sores, pneumonia, and urinary tract infections. Nearly one in five hip fracture patients ends up in a nursing home, a situation that a majority of participants in one study compared unfavorably to death.
- Fractures can also have a negative impact on self-esteem, body image, and mood, which may lead to psychological consequences. Individuals who suffer fractures may be immobilized by a fear of falling and suffering additional fractures. Not surprisingly, they may begin to feel isolated and helpless.
- Many bone disorders other than osteoporosis add greatly to the burden of bone disease in the population, although the impact varies enormously and is largely dependent upon the severity of the disease.

Chapter 5

THE BURDEN OF BONE DISEASE

Bone diseases have a major impact on the population as a whole and especially on affected individuals and their families. Osteoporosis, in particular, is an important public health problem that affects a large segment of the community. Although some bone diseases lead directly to pain and deformity, bone disease more commonly is a "silent" disorder until it causes one or more fractures. The many individuals with bone disease who suffer fractures must deal with the complications that may ensue, including ill health (morbidity), disability, a reduced quality of life, and possibly even death. The care of patients with these fractures is also very expensive, and costs will continue to rise as the frequency of bone disease increases in the future with the anticipated growth of the elderly population. These aspects of the problem are reviewed in the sections that follow, focusing first on the effects of bone disease on society as a whole and then on the problems that bone diseases pose for individuals. What these statistics make clear is that the burden of bone disease is enormous.

Most of the statistics that follow relate to osteoporosis, the most common and perhaps most "burdensome" bone disease from society's perspective. While the burden of osteoporosis has been well documented, there is relatively little information on the burden imposed by other disorders that affect bone health, even though they can cause marked impairment of health and even death in those who are affected. Recognizing the limits on available information, this chapter nonetheless provides some general descriptions on the burden of these other bone diseases on page 102.

Impact on Society

Mortality

Despite the large numbers affected, very few people die as a direct result of bone disease, although bone disease may be under-appreciated as an indirect cause of death. Bone diseases accounted directly for only a tiny fraction of the 2.4 million deaths reported nationally in 1999 (NCHS 1999). Other diseases, such as heart disease and cancer, are much more likely to directly cause an individual's death. Even hip fractures, which represent one of the most serious consequences of bone disease, seldom directly result in death. In fact, in 1999 hip fractures were listed as the cause of death on only 12,661 death certificates (NCHS 1999), representing less than 4 percent of the number of patients who were hospitalized for hip fractures in that year (Popovic 2001). Bone disease can indirectly lead to death, as fractures and their associated complications can in some cases trigger a downward spiral in health. In one population sample, the risk of mortality was four times greater among hip fracture patients during the first 3 months after the fracture than was the comparable risk among fracture-free individuals

The Real-Life Burden of Osteoporosis

Osteoporosis has a significant impact on the everyday lives of those who suffer from the disease, as the following story clearly illustrates.

This 73-year-old wife and grandmother suffered her first fracture 18 years ago and has had eight additional fractures since that time. Each caused tremendous pain and required long hospital stays and extended periods on medication. Unfortunately, however, because she does not tolerate osteoporosis medications well, her primary treatment has consisted of estrogen, vitamin D, and calcium supplements. As bad as the actual fractures have been, it is the fear of additional fractures that may well have the largest impact on her life. As a result of this fear, she limits the time she spends with her grandchildren, as well as the types of activities she enjoys with them (three of her fractures occurred while playing with her grandchildren). She finds it impossible to lie down on her back or right side and difficult to get in and out of bed or a chair. She has had to give up dancing, one of her favorite activities, and feels she has become a "drag" on family members who must slow down to accommodate her limitations.

"I had planned to spend these years enjoying my grandchildren, but I've really had to curtail my activities with them. I've fractured my back three times while playing with them."
—Long-time osteoporosis sufferer

A Parent's Perspective on the Burden of Bone Disease

This story illustrates the devastating impact that bone disease can have in those rare instances when it strikes children.

This mother has two children with bone disease. Her daughter, now in her mid-20s, suffers from osteoporosis. Yet it is her son's battle with severe OI that is most tragic. Now in his late 20s, he suffered nearly a dozen bone fractures at birth. When he was two months old, the mother endured the horrible sound of hearing her son's arm break as she turned him over in his crib. To date, he has suffered 140 fractures, some caused by acts as simple as sneezing or being startled. Fractures, however, are not the only health problems he faces. Like many OI sufferers, he also must live with scoliosis, broken teeth, hernias, kidney stones, and hearing loss. He presently requires full-time oxygen. Only 3 feet tall, he has never slept through the night.

Like many OI patients, he is highly intelligent and engaging, a true joy to be around. He spoke in complete sentences by the age of 1 and was reading at the age of 2. He showed an interest in politics by age 5, querying his mother on whom she was going to vote for in the presidential election and why. His tremendous intellectual abilities and engaging personality are as much or more a part of him as are his disabilities. His personality and story make him an excellent spokesperson for the disease.

of similar gender and age. Approximately 20 percent of the hip fracture patients died within a year of the fracture (Leibson et al. 2002). These overall rates may overstate the increased risk of death that is attributable to the fracture, as some of these patients were already in a nursing home and may have died even in the absence of the fracture. Another study, which included only patients who were ambulatory and not living in nursing homes at the time of their hip fracture, found that hip fracture patients had a 2.8-fold increased risk of dying during the 3 months following the fracture, although this risk also depended on their pre-fracture health. Those with poor pre-fracture health had higher mortality rates (Richmond et al. 2003). A recent analysis of NHANES I found that, over a follow-up period of 8–22 years, each standard deviation decrease in bone density was associated with a 10–40 percent increase in mortality (Mussolino et al. 2003). A prospective study of women over 65 (which was part of the Study of Osteoporotic Fractures) showed that each standard deviation of bone loss at the hip was associated with a 30 percent increase in total mortality (Kado et al. 2000). Recent studies from Sweden have shown increased mortality after spine fractures as well as hip fractures (Kanis et al. 2004, Johnell et al. 2004).

Morbidity

Bone diseases are much more likely to lead to poor health (i.e., morbidity) than they are to cause death. Most bone diseases disproportionately affect the elderly, who may already have substantial problems with frailty and reduced functional capacity. Fractures are the biggest problem facing most individuals with bone disease, especially those with osteoporosis. The cumulative impact of these fractures is quite devastating. As shown in Table 5-1, osteoporotic fractures in the United States in 1995 led to more than half a million hospitalizations, over 800,000 emergency room encounters, more than 2.6 million physician office visits, and the placement of nearly 180,000 individuals into nursing homes. Based on a statistical model, it has been estimated that over a 10-year period White women age 45 and older in the United States could experience 5.2 million fractures of the hip, spine, or forearm, resulting in 2 million person-years of disability related to the fractures (Chrischilles et al. 1994). Unfortunately, comparable estimates are not available for other diseases of the skeleton.

Hip fractures are by far the most devastating type of fracture, accounting for about 300,000 hospitalizations each year. Almost all hip fracture patients are hospitalized, and they represent nearly half of all hospitalizations for osteoporotic fractures in the United States (Table5-1). Hip fractures frequently lead to disability. More than one in four (26 percent) individuals suffering a hip fracture becomes disabled in the following year because of the fracture (i.e., this figure represents disabilities that are in addition to those resulting from the functional losses that would ordinarily occur in frail older persons) (Magaziner et al. 2003). Due primarily to dementia and the inability to walk independently, nearly one out of five requires long-term nursing home care (Table 5-2). In aggregate, hip fractures were responsible for nearly 140,000 nursing home admissions in 1995 (Ray et al. 1997). Spine fractures are less devastating, with only 1 in 10 patients requiring hospitalization and less than 2 percent requiring nursing home care (Chrischilles et al. 1991). They account for nearly 66,000 physician office visits and at least 45,000—and perhaps as many as 70,000—hospital admissions each year (Table 5-1). Half of these patients require some continuing care in a skilled nursing facility

Table 5–1. Resource Utilization Attributable to Osteoporotic Fractures Among Persons ≥ 45 Years of Age in the United States in 1995, by Type of Service and Type of Fracture

Type of service	Total	Type of fracture			
		Hip%	Forearm%	Spine%	Other sites%†
Inpatient hospitalizations	547,000	49	3	8	39
Nursing home residents	179,000	77	1	3	20
Physician Visits	2,634,000	14	20	3	63
Emergency room encounters	807,000	21	9	4	66
Physical therapy sessions	194,000	23	39	1	38
Diagnostic radiology	1,902,000	18	17	4	62
Medications	2,358,000	13	13	3	71
Home health care visits	2,250,000	60	2	3	35
Ambulance encounters	220,000	36	0	10	55
Orthopedic/other supplies	492,000	28	0	9	63

† These include fractures of the arm, lower leg, pelvis, ribs, ankle, and foot. The role of osteoporosis in fractures at other sites depends on age, race, and gender. There is disagreement about how many of these are osteoporotic-related fractures, although estimates range from 15% to 60%.

Source: Modified from Ray et al. 1997. Reproduced from J Bone Miner Res 1997: Jan; 12(1): 24–35 with permission of the American Society for Bone and Mineral Research.

(Gehlbach et al. 2003). Fractures of the wrist (also known as the distal forearm) are the least debilitating. Only about one-fifth of patients suffering a wrist fracture are hospitalized, and they rarely require nursing home care (Tables 5-1, 5-2). Yet even this relatively less traumatic event still accounts for nearly 20,000 hospital admissions and over 530,000 physician visits each year (Table 5-1). Surprisingly, these fractures consume more outpatient physical therapy services than do hip fractures.

Cost

Bone diseases are expensive, in terms of direct health care expenditures and indirect expenditures as well as lost productivity/workdays for patients and caregivers. While the figures cited below are large, it is important to remember that they represent today's costs. Given health care inflation and the projections for significant increases in the number of fractures (see Chapter 4), it is not unreasonable to assume that the direct and indirect costs of bone disease will more than double or triple in the coming decades (Burge et al. 2003).

Direct Costs

Studies show that annual direct care expenditures for osteoporotic fractures range from $12.2–$17.9 billion per year in 2002 dollars (Tosteson 1999). While women account for the majority of these costs, White men also incur substantial overall costs for osteoporotic fracture care (representing 18 percent of the total costs of osteoporosis, or $3.2 billion). In addition, non-White women and men of all ages account for $1 billion annually in total direct care expenditures on osteoporotic fractures (Ray et al. 1997).

Although large, expenditures related to osteoporosis represent just 7 percent of total heath care costs among women age 45 and older (Hoerger et al. 1999). This is more than double the amount spent for gynecological cancers but only a fraction of the cost of cardiovascular disease. However, osteoporosis accounts for nearly 14 percent of all nursing home days, due to the late age at which expenses are incurred for osteoporosis relative to other diseases (Hoerger et al. 1999).

Table 5–2. Disability Resulting From Osteoporotic Fractures

	Functionally dependent† (%)	Nursing home (%)
Hip fracture	10	19
Spine fracture	4	2
Forearm fracture	2	—
Any of these	7	8

† Community dwelling but requiring human assistance or unable to perform one or more activities of daily living.

Source: Chrischilles et al. 1991.

Hospital care accounts for more than half of the total direct costs, with nursing home care also responsible for a large portion of the total. As noted, hip fractures are the most devastating complication of osteoporosis, and therefore it is no surprise that they account for the largest proportion (63 percent or $11.3 billion) of medical care costs (Table 5-3). This is because hip fractures are very expensive to treat, with per-fracture costs estimated to range from $30,100–$43,400 in 2002 dollars (Tosteson 1999). The costs of caring for hip fractures are not limited to this initial treatment, however, as those suffering hip fractures require follow-up care as a direct result of their injury. A recent study estimated that hospital and outpatient care (excluding nursing home care) due to a hip fracture adds $14,600 to direct medical expenditures in the year following the fracture (Gabriel et al. 2002). The overall lifetime cost attributable to a hip fracture could exceed $81,000 (Braithwaite et al. 2003).

Although hip fractures account for the majority of costs, more than $6.5 billion is spent annually to treat those suffering from other types of osteoporotic fractures (Ray et al. 1997).

The direct costs of osteoporotic fractures are typically borne by society, primarily through Medicare and Medicaid. Among women over age 45, the government pays for most of the costs of osteoporotic fractures: Medicaid covers almost a fourth of the expense and Medicare pays nearly half (Hoerger et al. 1999). This is to be expected since nearly three-quarters of

Table 5–3. Direct Health Care Expenditures for Care of Osteoporotic Fractures Among Persons ≥45 Years of Age in the United States by Type of Service and Type of Fracture, 1995

Type of fracture	Type of service (millions of $)						
	Inpatient hospital	Emergency room	Outpatient physician	Outpatient hospital	Other outpatient*	Nursing home	Total
Hip	5576	130	67	9	90	2811	8682
Forearm	183	55	93	8	4	41	385
Spine	575	20	13	3	10	126	746
All other sites†	2259	3632	297	45	91	899	3953
Total	8594	567	470	65	194	3875	13,764

*Includes home health care, ambulance services, and medical equipment.
† Depending on age, race, and gender, from 15% to 60% of all other fractures were attributed to osteoporosis

Source: Ray et al. 1997. Reproduced from J Bone Miner Res 1997: Jan; 12(1): 24–25 with permission of the American Society for Bone and Mineral Research.

all hip, spine, and distal forearm fractures occur among patients 65 years and over.

Indirect Costs

In addition to imposing direct medical costs on society, osteoporosis also results in indirect costs, primarily related to reduced productivity due to disability and premature death. Indirect costs are inherently difficult to measure, and much more needs to be done in this area. One method judges lost productivity on the basis of reduced earnings. For bone diseases, which affect a large number of retired persons, indirect costs are underestimated by this approach. Nonetheless, assuming that people are worth what they earn, one study estimates that the cost of premature death and of restricted activity resulting from fractures accounts for 26 percent of total fracture costs and 12 percent of hip fracture costs (Praemer et al. 1999). A recent study from California (where 12 percent of the US population resides) found that the indirect cost to society (based only on lost earnings from premature deaths) accounted for 17 percent of the total cost related to osteoporosis (Max et al. 2002).

Impact on the Individual

While the statistics cited in the previous section relate to the impact of bone disease on society, it is important to remember that these "global" statistics really take on meaning when examining what they mean for individuals. In fact, osteoporosis and other bone diseases have a profound impact on those individuals who suffer from them and on their families. This section examines that impact, highlighting the very real burden that bone disease can place on the physical health, mental well-being, and financial stability of those individuals and family members affected by the disease.

The Chance of Dying From Bone Disease

While the chance of dying varies by fracture type, the vast majority of individuals suffering from osteoporosis and osteoporotic-related fractures do not die directly as a result of their disease. As noted previously, hip fractures are among the most devastating type of fracture; it has been estimated that approximately 20 percent of all patients die within a year (Leibson et al. 2002). The oldest hip fracture patients are most likely to die, and survival rates are lower for men (both White and Black) than for women, although Black women are more likely to die from a hip fracture than are White women. These differences may be due in part to the older age at which men and Black women are likely to suffer a hip fracture as well as to differences in their medical care (Figure 5-1). It is important to note, however, that the typical hip fracture patient is about 80 years old, and thus their risk of death from any cause is not trivial. Thus, it is more accurate to say that a hip fracture decreases the chance of survival in the first year by about 12–20 percent in this already at-risk population. Another way to look at this statistic is that 9 out of every 100 women with a hip fracture will die as a result of the fracture (Magaziner et al. 1997). The increased risk of death is especially high (10 times more than the expected death rate) in the first few weeks following a hip fracture. While the excess risk of death due to hip fractures diminishes with time, there may still be some additional risk for a number of years. For example, roughly 5 percent of hip fracture patients experience a severe medical complication, causing an increase in their risk of death (Lawrence et al. 2002). In addition, as noted previously, most hip fracture patients have other serious medical problems (comorbidities that more directly contribute to death) (Browner et al. 1996). Even so, with any given amount of preexisting comorbidity, the occurrence of a hip fracture substantially increases the likelihood of dying (Poór et al. 1995).

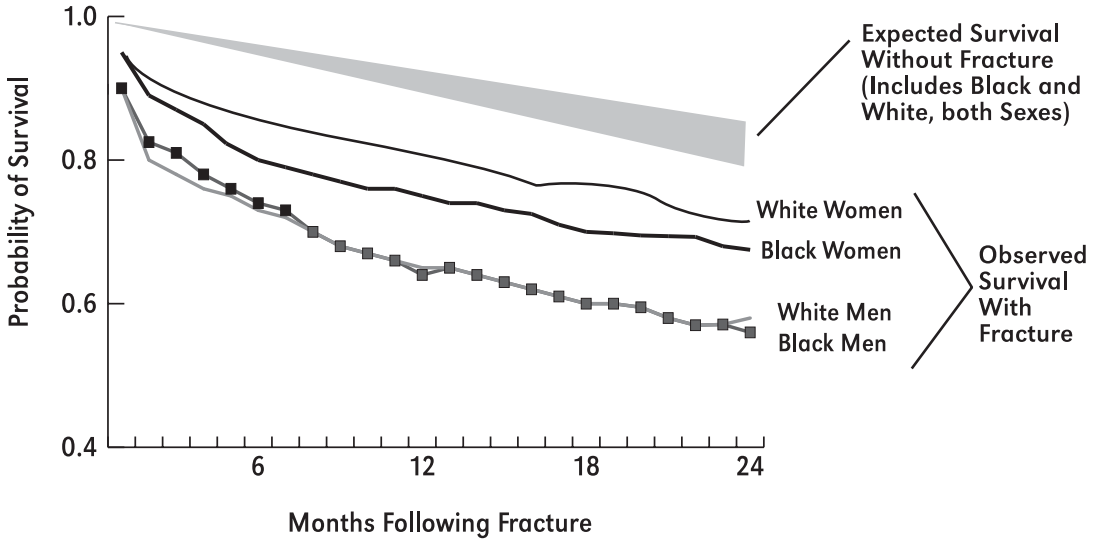
Other types of fractures are less likely to result in death. For example, patients suffering a wrist fracture are no more likely to die than anyone else (Melton 2003). Other limb fractures have been linked to an increased risk of death (Browner et al. 1996), although only a few of these deaths are related directly to the fracture. Most of the deaths seem to result from the presence of some other serious disease. For example, the death rate following a fracture of the spine is 1.2 to 1.9 times greater than expected (Melton 2003), but most of the deaths occur long after the fracture and appear to be due to serious underlying medical conditions that not only increase the risk of dying but also are likely the cause of the bone loss and associated fractures.

As noted in Chapter 3, inherited bone diseases have been found to increase the risk of death; in fact, in some cases these diseases are so severe that they are incompatible with life. Likewise, survival is much reduced among patients with bone cancer and multiple myeloma (Praemer et al. 1999). It is unclear whether or not patients with primary hyperparathyroidism face an increased risk of death, although survival does appear to be worse for the most severely affected patients, including those with the highest blood calcium levels and those with other serious diseases (Vestergaard et al. 2003).

Impact on Morbidity, Levels of Disability, and Functional Status

Bone diseases dramatically affect the functional status of those who get them. Many individuals who suffer fractures as a result of osteoporosis suffer significant pain, height loss, and may lose the ability to dress themselves, stand up, and walk. These patients are also at risk of acute complications such as pressure sores,

Figure 5–1. Observed and Expected Race- and Sex-Specific Survival Following Fracture of the Hip, All Ages Combined

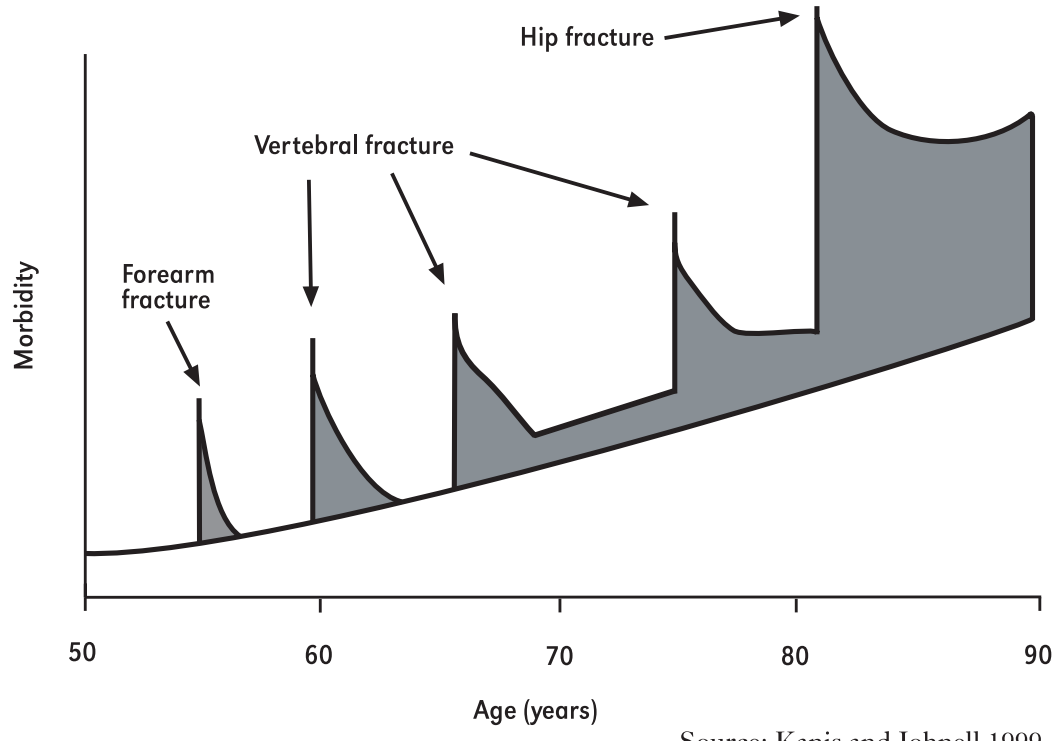


Source: Based on Jacobsen 1992.

pneumonia, and urinary tract infections. Nearly one in five ends up in a nursing home, a situation that a majority of participants in one study compared unfavorably to death (Salkeld et al. 2000). As illustrated in Figure 5-2, different types of osteoporotic fractures have a different impact on the patients who suffer them. Wrist fractures commonly occur in women in their mid-50s and usually have only a short-term impact, whereas spine fractures typically occur at a later age and may give rise to permanent morbidity. By contrast, hip fractures occur later in life (around age 80 on average) and usually result in permanent disability (Kanis and Johnell 1999). Each of these fracture types will be discussed in more detail below.

Two-thirds of hip fracture patients do not return to the level of function they enjoyed before the fracture (OTA 1994), particularly those who become depressed (Magaziner et al. 2003). Many lose their ability to walk. In fact, only 40–79 percent of patients regain their previous ambulatory function a year after the fracture, and less than half return to their prefracture status with respect to the activities of daily living (Greendale and Barrett-Connor 2001). For example, data from the Established Populations for Epidemiologic Studies of the Elderly (EPESE) project show that 86 percent of patients could dress by themselves before the fracture, but only 49 percent afterwards. Similarly, 90 percent could move from chair to

Figure 5–2. Schematic Representation of the Morbidity Associated With Different Osteoporotic Fractures with Age



Source: Kanis and Johnell 1999.

standing before the fracture and only 32 percent after. Comparable figures for walking across the room are 75 percent and 15 percent (Marottoli et al. 1992). Indeed, hip fracture patients are as likely to have impaired ambulation and other functional deficits as are those who suffer a stroke (Lieberman et al. 1999). Even among people who were previously independent, many activities cannot be carried out independently following a hip fracture (Table 5-4). Hip fractures cause an "extra" 10 percent of women to become functionally dependent (i.e., 10 percent more women become dependent than would have in the absence of the fractures), and 19 percent of women who suffer hip fractures require long-term nursing home care (Chrischilles et al. 1991).

Other types of fractures, while somewhat less devastating than hip fracture, nevertheless take a toll on those who suffer them. For example, while spine fractures rarely cause institutionalization (Chrischilles et al. 1991), their adverse influence on most activities of daily living is almost as great as that seen for hip fractures (Greendale et al. 1995).

This loss in functional status is mainly the result of the pain caused by spine fractures. New spine fractures may produce severe back pain that lasts for weeks or months (Ross 1997). Ettinger and colleagues found that 50 percent of elderly women had a mild or moderate spine deformity on x-ray, yet they were only slightly more likely to have constant or severe back pain, back disability, or substantial height loss than those with no evidence of a spine fracture (Ettinger et al. 1992). Ten percent of the elderly women in this study had a severe spine deformity, and this group showed a significantly increased risk of these problems, especially in those individuals with fractures in multiple vertebrae. Not surprisingly, the more severe fractures are also the most likely to be diagnosed, and thus they represent the vast majority of spine fractures that are recognized clinically. However, even spine fractures that escape diagnosis can cause an increase in back pain and limited activity (Nevitt et al. 1998).

Wrist fractures seldom cause long-term disability, but they nonetheless are painful, requiring repositioning of the bones to their normal position and stabilization in a cast for 4–6 weeks. Recent studies suggest that wrist fractures may cause a number of short-term problems, including persistent pain, loss of function, nerve impairments (such as carpal tunnel syndrome), bone deformities, and arthritis (Greendale and Barrett-Connor 2001). In fact, nearly half of all patients report only fair or poor functional outcomes 6 months following a wrist fracture. Women and the elderly are the most likely to report such outcomes. There is no question that the overall impact of wrist fractures on a patient's functional status is much less than that of a hip fracture. In fact, less than 1 percent of wrist fracture patients become completely dependent as a result of the fracture (Chrischilles et al. 1991). These fractures may be as disabling as hip fractures with respect to some specific activities of daily living such as meal preparation.

Finally, while they are less devastating than hip fractures, spine, wrist, and the other limb fractures are more common, and they are the main contributors to osteoporosis-related morbidity in middle-aged women and men (Kanis et al. 2001). In addition, the occurrence of one of these fractures is a strong risk factor for additional fractures (see Chapter 8).

Impact on Emotional State

In addition to functional impairments, fractures from bone disease can have a negative impact on self-esteem, body image, and mood (Ross 1997), which may lead to psychological

Table 5–4. Postfracture Dependency† at 12 and 24 Months Among Patients Who Were Independent Prior to Hip Fracture

	12 months %	24 months %
Lower extremity physical activity of daily living		
Climbing five stairs	90	91
Getting in/out of bath/shower	83	83
Walking one block	55	53
Getting into a car	45	50
Rising from an armless chair	50	54
Walking 10 feet	40	37
Taking a shower/bath/sponge bath	38	44
Getting on/off the toilet	66	63
Putting socks and shoes on	33	33
Getting in/out of bath	31	33
Putting on pants	20	20
Instrumental activities of daily living		
Housecleaning	62	43
Getting places out of walking distance	53	53
Shopping	42	41
Cooking	24	23
Handling money	31	31
Taking medications	28	29
Using the telephone	22	23

† Dependency is defined as the need for either human or equipment assistance or inability to perform the activity due to health reasons.

Source: Magaziner et al. 2000.

consequences (Gold et al. 2001). Individuals who suffer fractures may be immobilized by a fear of falling and suffering additional fractures. Not surprisingly, they may begin to feel isolated and helpless. In a survey conducted by the National Osteoporosis Foundation, 89 percent of women who had already had an osteoporotic fracture said they feared breaking another bone; 80 percent were afraid that they would be less able to perform their daily activities; 80 percent feared losing their independence; 73 percent were concerned that they would have to reduce activities with family and friends; and 68 percent worried that another fracture would result in their having to enter a nursing home. If not addressed, fear about the future and a sense of

helplessness can produce significant anxiety and depression. These problems may be compounded by an inability to fulfill occupational, domestic, or social duties (Table 5-5), thus leading to further social isolation.

Impact on Quality of Life

Not surprisingly, the increased levels of morbidity and disability and the declines in functional status and mental health that are typically associated with bone disease and fractures can have a profound impact on an individual's quality of life. Some studies have begun to address these intangible aspects of osteoporosis and other bone diseases by having individuals rate their quality of life in a given year, using a measure known as quality-adjusted life years (QALYs). When estimating QALYs, each year of life is assigned a preference weight between 1 and 0, where 1 represents perfect health and 0 represents death. Different individuals with similar health status may rate the quality of their life very differently, depending upon how they personally value that health status compared to being in perfect health and to dying. While results vary depending on the type of fracture being measured, patient age, and the assessment technique used, individuals suffering osteoporotic-related fractures consistently report significant reductions in QALYs; these reductions range from 0.05–0.55 on the 0 to 1 scale mentioned above (Tosteson and Hammond 2002). For example, spine

Table 5–5. Clinical Consequences of Spine Fractures

Symptoms	Signs	Function	Future risks
Back pain (acute, chronic) Sleep disturbance Anxiety Depression Decreased self-esteem Fear of future fracture and falling Reduced quality of life Early satiety	Height loss Kyphosis Decreased lumbar lordosis Protuberant abdomen Reduced lung function Weight loss	Impaired activities in daily living (e.g., bathing, dressing) Difficulty fitting clothes due to kyphosis, protuberant abdomen Difficulty bending, lifting, descending stairs, cooking	Increased risk of fracture Increased risk of death

Source: Papaioannou et al. 2002. Reprinted from The American Journal of Medicine, Diagnosis and management of vertebral fractures in elderly adults. 113(3): 220–228 (2002), with permission from Excerpta Medica, Inc.

fractures are associated with a 20 percent reduction in the quality of life in the first 12 months and a 15 percent reduction after two years (Tosteson et al. 2001). Even those who manage to remain independent following a fracture typically experience a substantially reduced quality of life. For example, relatively healthy survivors of a hip fracture report a 52 percent reduction in quality of life in the first 12 months and a 21 percent reduction after two years (Tosteson et al. 2001). Similar differences were seen in a recent study comparing function and quality of life in Belgian women with a hip fracture compared to age-matched controls (Boonen et al. 2004). Health-related quality of life is also decreased in patients with spine fractures, particularly those who have had repeated episodes (Cockerill et al. 2004). Quality of life is also reduced in patients with other bone diseases. For example, patients with Paget's disease report a high frequency of hearing loss and boney deformities, but many also report depression (53.4 percent), sleep problems (51.5 percent), and poor quality of life (42.1 percent report poor or fair QOL). In the only published study to explore factors related to QOL in Paget's disease (Gold et al. 1996), the authors found that the psychological factors (including depression and loss of self-esteem) were the most important contributors to reduced QOL in these patients; they explained more of the variance (19 percent) in QOL than did biomedical (3 percent), social (2 percent), or cost (1 percent) factors. They also found that QOL was significantly decreased in patients with more extensive or symptomatic Paget's disease. These data, combined with similar data from studies of osteoporosis, suggest that the negative impact of bone disease is substantial.

Impact on Financial Well-Being

In addition to a decline in physical and mental health, patients with bone disease also bear significant financial expenses. Although better information is needed, these patients often must pay for a variety of expenses out of their own pockets (Table 5-6), creating a financial burden for many patients and their families. Hoerger and colleagues estimated that 17 percent of the cost of managing osteoporosis is not covered by insurance (i.e., Medicare, Medicaid, or private coverage) (Hoerger et al. 1999). Patients and/or family members may be responsible for some proportion of the average $2,000 increase in direct medical expenses that occur in the year following a fracture (Gabriel et al. 2002). They may also have to pay a portion of the cost of any drug therapy to prevent additional fractures (these costs are not included in the $2,000 figure cited above) and to bear the costs associated with disability during the recovery period and over the long term. Furthermore, younger family members may experience reductions in earning power as they take time away from work to assist older patients during the convalescence period (Brainsky et al. 1997); few studies to date have accounted for this type of lost productivity among individuals who must care for those who sustain fractures. Even if the hours of care provided by family and friends (informal care) are valued at the minimum wage, they represent a substantial proportion of the overall costs of care in the first 6 months following a hip fracture (Table 5-6). While the proportion of total care costs represented by informal care actually drop following a fracture (due to the high expenses of treating the fracture), the absolute dollar value of these costs more than doubles in the first 6 months after the fracture.

The Burden of Other Bone Diseases

As indicated in Chapter 4, thousands of Americans are affected by other bone diseases such as rickets and osteomalacia, renal osteodystrophy, primary hyperparathyroidism, Paget's disease, osteogenesis imperfecta, bone cancer, and other developmental and acquired skeletal disorders. Estimates of the societal burden of these conditions are not readily available. The impact of these conditions on individuals, moreover, varies enormously, and is largely dependent upon the severity of the disease.

The majority of patients with primary hyperparathyroidism are asymptomatic, but a small number suffer from kidney stones, fractures, or rarely dangerously high blood calcium levels that can lead to severe impairment of kidney function, coma, and death. Most Paget's disease patients suffer from pain, but some also develop nerve damage, fractures, or osteosarcoma (a type of bone cancer). Few patients with Paget's disease die from the condition, although, as discussed earlier, they often find their QOL to be reduced significantly because of the disease. Some patients with

Table 5–6. Costs Per Month Per Patient, Before and After Hip Fracture, Adjusted for Death and Excluding the Cost of the Initial Hospitalization

	($/month/patient) Before fracture	After fracture
	Previous 6 months	First 6 months
Other hospitalizations	255	1015
Nursing home stays	6	864
Rehabilitation	4	681
Physician visits	24	103
Nurse/aide visits	10	77
Home aide services	133	445
Physical therapy	8	58
Durable equipment	11	111
Meals-on-wheels	4	9
Arranging services	1	5
Transportation	17	43
Emotional support	27	132
Informal care	1244	2517
Total per month	1744	6060

Source: Brainsky et al. 1997.

chronic renal disease who are on dialysis develop a severely debilitating bone disorder that results in pain and fractures. Others lose bone rapidly after renal transplantation and, despite the successful improvement of their kidney function, have poor health because of fractures.

Among the genetic skeletal disorders, the dense bones associated with osteopetrosis and the fragile bones associated with osteogenesis imperfecta (OI) can both cause severe illness. While some patients with osteopetrosis can be treated by bone marrow transplantation and others with stimulators of bone breakdown, success has been limited and many patients die from these conditions. OI often causes severe crippling and in its most severe form is fatal, although treatment with inhibitors of bone breakdown appears to be effective and is being explored further. (See box on page 90 for an example of OI's impact on an individual patient.) Cancer in bone often causes severe symptoms and frequently leads to death. Myeloma causes severe pain and bone loss with multiple fractures. Other types of cancer, including breast and prostate, can spread (metastasize) to bone, although (as discussed in Chapter 9) this can be reduced by treatments that block bone breakdown (Ross et al. 2004, Rosen et al. 2004).

In summary, there are a number of disorders other than osteoporosis that add greatly to the burden of bone disease in our population. Fortunately, the ability to diagnosis and treat many of these disorders has improved in recent years (see Chapters 8 and 9), thus making it possible to reduce this burden substantially in the future.

Key Questions for Future Research

Much more information on the frequency and burden of osteoporosis and other bone diseases is needed if plans to prevent the projected "epidemic" are to be successful. Careful collection of national and local data on all osteoporotic-related fracture types is needed so that progress in meeting prevention goals can be measured. Specific research questions that need to be answered include the following:

- How common are fractures in the community? Better data on fractures identified in physician's offices as well as in hospitals are needed.
- How common are hip fractures among the Medicare and non-Medicare population? What are the trends over time and across geographic regions and racial and ethnic groups?
- What is the true incidence and burden of spine fractures, given that many are "silent"? Surveys using dual x-ray absorptiometry (DXA) to assess spine deformities may help to answer this question.
- What is the impact of non-hip fragility fractures on morbidity, mortality, and quality of life?
- What is the impact on quality of life of asymptomatic spine fractures? These fractures may cause deformity and musculoskeletal symptoms such as low back pain, and may negatively affect cardiopulmonary and gastrointestinal function.
- What are the economic costs of osteoporosis and fragility fractures? While some data are presented in this chapter, more detail is needed, including information on non-Medicare patients, men, and racial and ethnic minorities.
- What is the prevalence and burden of osteoporosis and the incidence and burden of fractures in men and racial and ethnic minorities, including Blacks, Asians, and Hispanics?

- What environmental factors are responsible for geographic variations in fracture rates?
- What is the prevalence and burden of bone diseases and disorders other than osteoporosis, including hyperparathyroidism, osteomalacia, renal osteodystrophy, osteogenesis imperfecta, and congenital disorders affecting bone such as osteopetrosis? This examination of other bone diseases should include a review of their impact on racial and ethnic minorities.
- What impact do the skeletal implications of malignancy have on morbidity, mortality, and quality of life?
- What is the projected incidence and burden of bone disease if current practice is maintained and how much could these be changed by various levels of improvement in awareness, diagnosis, prevention, and treatment of bone disease?

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