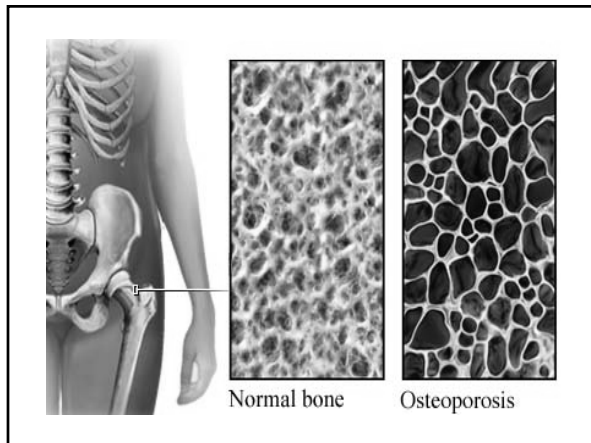




Osteoporosis is a largely under-diagnosed condition.

- Often diagnosed after a fracture
- Patient may be asymptomatic prior to fracture
- Low bone mass density (BMD) is considered the "disease"
- Fragility fractures are the "consequences" of the disease

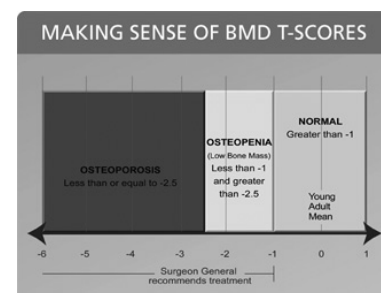


Those affected:

- In older women, incidence of osteoporotic fractures is greater than incidence of myocardial infarction, stroke, and breast cancer combined.
- Can appear in both men and women, adults & children
- Osteoporosis and fractures are not solely the outcome of post-menopausal women

According to the National Osteoporosis Foundation (NOF):

- 44 million people in the U.S. have low BMD ($< 1\text{g}/\text{cm}^2$)
 - 10 million of those have osteoporosis
 - 34 million have osteopenia and are at risk of for osteoporosis
- Projection: By 2020 there will be almost 14 million Americans with osteoporosis.

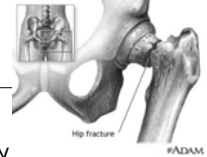


U.S. Fracture Incidence:

- | | |
|--|--|
| <p>□ Approx. 1.5 million people per year have osteoporosis-related fragility fractures:</p> <ul style="list-style-type: none"> ■ 700,000 spine ■ 300,000 hip ■ 250,000 wrist ■ 300,000 other | <p>□ Economic costs, including rehab, hospitalization, and nursing home care:</p> <ul style="list-style-type: none"> ■ Direct cost in 1995 - \$13.8 billion ■ 2003 - \$17 billion ■ 2008 - \$21 billion |
|--|--|

www.NOF.org

Hip Fractures



Complications:

- 24-30% excess mortality within 1 year (nearly 65,000 women)
- 50% survivors are incapacitated
- 20% survivors require long-term nursing home care
- Failure to diagnose and treat osteoporosis
- One study – 170 patients hospitalized for hip fracture, diagnosis & treatment for osteoporosis occurred in < 10%

(Kamel HK, et al. Am J Med 2000; 109:326-328).

“Low bone mass” which defines the diagnosis of osteoporosis may have multiple causes.

- Vitamin D deficiency
- Cushing’s disease
- Hyperparathyroidism
- Hyperthyroidism
- Drug toxicity
- Immobility
- Hypogonadism (in both men and women)

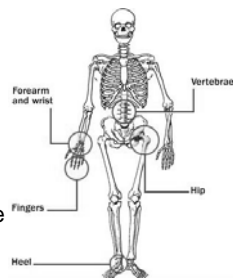
Other populations at risk include persons with:

- Extensive steroid use
- Eating disorders
- Persistent amenorrhea
- Low sex-hormone levels
- Thyroid disease
- Developmental disabilities

Few studies have reported fracture rates in developmentally disabled (DD) individuals.

• Fractures do not appear to be unusual in the DD population

• Cause is often undeterminable



Research

- **Tannenbaum** – studied mental retardation at an intermediate care facility – Over 500 persons were 4X more likely to have a fracture than U.S. population fracture rate
- **Lohiya et. al.** – studied over 1000 residents at a DD center – fracture rate 1.7X greater than that in U.S. population
- **Tyler** – studied prevalence of osteoporosis in community-dwelling adults with mental retardation – over 50% had either osteoporosis or osteopenia

Diagnosis

- Usually begins with a DEXA scan, which is normally straightforward in the general population
- Adults with DD may present with contractures, deformities, and movement disorders that may confound analysis of BMD
- May want to consider obtaining metabolic bone markers



Treatment

- May require careful consideration of multiple co-morbid conditions
- No published studies which demonstrate efficacy of “bone-building” pharmaceuticals in persons with DD who may have low bone density due to multiple mechanisms
- Few medical specialists in treating metabolic bone disorders that are experienced with the health problems in DD population



- Well established standards of care for the evaluation and management of osteoporosis and fractures in DD population are lacking.
- More clinical data and guidance are needed.
- Hunterdon Developmental Center (Clinton, NJ) began the “Healthy Bones Initiative” in August 2006, in an effort to proactively address these issues.

August 2006, Hunterdon Developmental Center purchased and began operating a full-size “GE Lunar Prodigy Advance Plus” standard table DEXA machine.



DATA COLLECTION

- Review of HDC records illustrated the following:
 - Prior only 44 individuals had ever received a DEXA scan prior to 2004. *Of those individuals, 34 (77%) were shown to have low BMD.*
 - 2004-2006: 76 individuals at HDC received DEXA scans
- August 2006-July 2008: HDC attempted to scan 328 individuals



DATA COLLECTION

Out of the 328 attempted scans 8/2006-7/2008:

- 46 individuals were uncooperative and could not be scanned
- 29 scans were unreadable due to poor positioning related to contractures or deformities
- 253 scans out of 328 attempts were readable and BMD was determined:
 - 156 (62%) were diagnosed with osteoporosis
 - 73 (29%) were diagnosed with osteopenia
 - 24 (9%) had normal BMD



DATA COLLECTION

Staff are now in the process of obtaining additional clinical information on all HDC residents scanned. This includes:

- Medications
- Vitamin D levels
- Associated Health Conditions



DATA COLLECTION

We are also looking specifically at osteoporosis treatment modalities and their efficacy in increasing Bone Mineral Density (BMD) of the hips and spine.



Pilot results have been obtained from 4 living units (a total of 66 individuals who have received DEXA scans).



- 38 individuals (57%) have a history of fracture
- 10 individuals have received both a baseline and 1 year follow-up DEXA scan.

DATA COLLECTION

Analysis of BMD from individuals who received baseline and follow-up DEXA Scans suggests the following:

- Calcium and Vitamin D alone are not sufficient to improve BMD
- Low BMD is more prevalent in the hips than in the spine
- Fosamax and Boniva *appear* to be more effective for low BMD of the spine, than they are for low BMD of the hips



OUTCOME ANALYSIS

It appears that many questions remain to be answered. HDC's "Healthy Bones Initiative" will perform the outcome analysis in conjunction with an ongoing multi-modal educational program.

To better discern the relationship of osteoporosis in the developmentally disabled individual, HDC will perform the following 6 steps:

OUTCOME ANALYSIS

1. Establish baseline BMD's for all individuals residing at HDC and perform follow-up DEXA scans yearly thereafter
2. Determine baseline and yearly number of individuals in the following categories: Normal, Osteopenia, Osteoporosis
3. Determine number of osteoporotic residents with etiology of osteoporosis established
4. Determine treatment modalities: None, Calcium/ Vitamin D, Exercise, Pharmaceutical
5. Determine number of residents with low baseline BMD who demonstrate a documented increase of BMD in response to intervention
6. Simultaneously determine individual and overall institutional fracture rates, baseline and at yearly intervals.

DISCUSSION



Although more data collection is necessary, preliminary findings of HDC's "Healthy Bones Initiative" demonstrates a high incidence of osteoporosis/osteopenia in its DD population.

Our findings thus far, coupled with existent research, could suggest that not only is there elevated *risk* of osteoporosis/osteopenia in DD individuals, but that there is an actual elevated *prevalence* of the disease in the developmentally disabled.

DISCUSSION



It's too early to state that bone-building pharmaceuticals are effective in the DD individuals; however, all available avenues of osteoporosis/osteopenia intervention should be evaluated.



Diagnosis, early detection, and intervention are the keys to adequately addressing this disease in the developmentally disabled.

DISCUSSION

Other healthcare practice centers may want to begin a "Healthy Bones Initiative" program.

With adequate identification, research, intervention, and data collection, perhaps this could become a health topic in the national arena.

