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Factors associated with the accuracy of self-reported osteoporosis in the community

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Abstract We examined the agreement between self-reported osteoporosis and bone mineral density (BMD) results through dual-energy x-ray absorptiometry (DXA) using data from a national representative sample taken from the US communities. Six-year data from the continuous National Health and Nutrition Examination Survey 2005–2006, 2007–2008, and 2009–2010 were merged. Participants included adults 50 years of age or older whose data appeared in both questionnaire and medical examination data files. Self-reported osteoporosis was defined by an affirmative response to a question in the osteoporosis questionnaire then compared with BMD-defined osteoporosis, defined by BMD values taken from the examination data. Agreement between self-reported osteoporosis and DXA results were low. Kappa was only 0.24 (95 % confidence interval = 0.21–0.27), and sensitivity and positive predictive value were 28.0 and 40.8 %, respectively. When stratified by gender or age group, agreement remained poor. Self-report of osteoporosis would not be suitable for accurate prevalence estimates for osteoporosis regardless of gender or age group.

Keywords Osteoporosis · Community survey · Bone density · Agreement · Sensitivity and specificity

Introduction

Worldwide, there are approximately 200 million individuals affected with osteoporosis, 10 million of which currently reside in the USA [1, 2]. In America, osteoporosis has caused 2 million fractures, over 400,000 hospital admissions, approximately 2.5 million office visits, and almost 200,000 nursing home admissions per year [3].

Osteoporosis diagnosis is most often established by a bone mineral density (BMD) measurement obtained by dual-energy x-ray absorptiometry (DXA) [4]. This method has been used as the gold standard for diagnosing asymptomatic osteoporosis [5, 6]. However, measuring BMD in large-scale epidemiologic or population-based studies is time consuming and expensive [7, 8]. Utilizing self-report data is one of the most practical methods to evaluate a disease status in larger communities. If recorded accurately, self-reports offer an economic, evidence-based estimate so treatment cost can be reduced significantly through the implementation of interventions, preventative measures, and policy changes [9, 10]. On the other hand, self-reports of osteoporosis are subjected to recall bias, misunderstanding of the BMD results, or the lack of awareness on the importance and severity of the disease [4, 5].

Previous studies documented the difference between self-reported data on osteoporosis and the actual BMD measurements [4, 5, 8]. In a study, Cadarette et al. [5] concluded a poor agreement between self-reported physician-diagnosed osteoporosis and DXA-documented osteoporosis on Canadian women aged 65–90 years. The authors also found that only 62 % subjects with osteoporosis and 29 % subjects with osteopenia reported the results of their most recent DXA scan correctly. Similarly, Peeters et al. [8] examined the consistency between self-reported osteoporosis and government medication records in an Australian

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longitudinal study on women's health. They found a low to moderate agreement between the two data sources. Most recently, Stuart et al. [4] examined data collected from 1749 Australian men and women in a population-based study and reported a poor overall agreement between self-reported osteoporosis and BMD results (kappa = 0.29) and low values of sensitivity and positive predictive value.

Though these sparse evidences showed an inconsistency between patient self-reported and BMD-defined osteoporosis, most of the studies included women only, and to the best of our knowledge no previous study was conducted on a large sample of US population. In addition, previous literature has shown a limited number of factors examined for any potential effect on the overall agreement of self-report and DXA results for osteoporosis. Such factors include race, marital status, overall health condition, alcohol consumption, family history of osteoporosis, access to healthcare, and other demographic and clinical characteristics [5, 10]. Since the quality of self-reported data is important to the accuracy of epidemiologic studies and to the ability to obtain robust estimates for policy or planning purposes, in this analysis we aimed to assess factors that are associated with the agreement of self-reported and BMD-defined osteoporosis using data taken from a 6-year period of a nationally representative household survey in the USA.

Materials and methods

Study design and data

The data for this study were downloaded from the continuous National Health and Nutrition Examination Survey (NHANES), a national survey conducted by the National Center for Health Statistics of the Centers for Disease Control and Prevention to assess the health and nutritional status of the non-institutionalized US civilian population. NHANES uses a stratified, multistage probability design to select the sample with a standardized procedure to collect data from questionnaires and medical examinations. Details of the survey design and methodology are published online [11]. To obtain a large and representative sample, we merged 6-year data from the continuous NHANES 2005–2006, 2007–2008, and 2009–2010. Data files of interest were linked through the unique respondent sequence number into a single large dataset. We included in our sample adults 50 years of age or older who appeared in both questionnaire and medical examination data files.

The primary outcomes for this study were self-reported osteoporosis and BMD-determined osteoporosis. Self-reported osteoporosis was defined by the responses to the osteoporosis questionnaire as part of NHANES. Subjects were considered to have self-reported osteoporosis if they responded "yes" to the question "Has a doctor ever told you that you had osteoporosis, sometimes called thin or brittle bones?" in the osteoporosis questionnaire. BMD-defined osteoporosis was identified by the examination data which recorded the BMD of the proximal femur measured using DXA at different regions of interest. In this study, we used BMD measurements from three regions: femoral neck, total femur, and total lumbar spine based on the Clinician's Guide to Prevention and Treatment of Osteoporosis developed by an expert committee of the National Osteoporosis Foundation (NOF) [3]. Subjects with a BMD value more than 2.5 SD below the BMD mean of the reference age group (20–29 years old) were considered having osteoporosis. Previous published data on BMD [12] were used to set up the reference cut points for the four regions of interest.

Questionnaire data were used to extract sample characteristics. Age was divided into two age groups, those 50–65 years old and those older than 65 years old, while race was categorized into four categories of non-Hispanic Black, non-Hispanic White, Mexican–American, and other or multiracial. Education was categorized as high school equivalent or less, some college, and college graduates or more. Dichotomous variables include gender (male/female), marital status (single/married or living with a partner), and annual family income (<\$55,000 or ≥\$55,000). Participants' self-evaluation of general health condition was grouped into three categories: Excellent or very good, good or fair, or poor. Body mass index (BMI) was categorized into three groups: BMI < 25 kg/m^2, 25 kg/m^2 ≤ BMI < 30 kg/m^2, or BMI ≥ 30 kg/m^2. Alcohol consumption was defined as nondrinker (0 drinks/day), light drinker (<4 drinks/day), or heavy drinker (≥4 drinks/day). The following clinical characteristics were coded as dichotomous variables: cigarette use (smoker/nonsmoker), family history (either one of the biological parents was diagnosed with osteoporosis/none), taking prednisone or cortisone daily (yes/no), having arthritis (yes/no), having a thyroid problem (yes/no), having seen a mental health professional in the last year (yes/no), and having ever been treated for osteoporosis based on prescription medications or self-reported response (yes/no). History of fractures of the hip, wrist, or spine was determined when participants responded "yes" to the question if they were ever told by their doctor to have broken or fractured their hip/wrist/spine, together with the response indicating that the reason for fractures was osteoporosis related. Fractures due to a car accident or hard fall were excluded. Concerning access to care, the following covariates and their corresponding categories were included as the indicators for access to healthcare: number of times received healthcare over the past year (0–3, 4–9, more than nine visits), the type of routine healthcare place most often visited [clinic or health center, doctor office or

health maintenance organization (HMO), hospital, some other place], and type of insurance (government, private or single plan, multiple plans, no insurance coverage). Government insurance includes Medicare, Medi-Gap, Medicaid, military healthcare, state-sponsored health plan or any other government insurance.

Statistical analysis

Descriptive statistics for each related survey item were reported. The means and standard deviations (SD) for continuous outcomes and frequencies and proportions for categorical outcomes were presented. To assess the agreement between self-reported questionnaire data and BMD data, Kappa coefficients, sensitivity, specificity, positive predictive values, and negative predictive values were calculated. To examine factors associated with the agreement between the two data sources, we created a binary variable which takes on the values of yes/no for the agreement. Logistic regression models were fitted to predict the probability of agreement. Both unadjusted and adjusted models were examined. In the adjusted model, stepwise selection method was used to obtain the best mathematical model that described the relationship between the binary variable representing agreement and all covariates of interest. Models were assessed based on goodness of fit using deviance Chi-square statistics and Akaike Information Criterion [13]. The analyses were stratified by gender and age group. All statistical calculations were performed in SAS 9.4 (SAS Institute Inc, Cary, NC, 2007). Statistical significance was determined at the level of alpha = 0.05.

Results

A total of 7994 individuals were included in the study sample. Table 1 displays the characteristics of the study sample. Approximately half of the sample were 50–65 years old, were male, and were non-Hispanic Whites. The majority of the samples were nonsmokers, did not take prednisone or cortisone daily, did not have a thyroid problem, did not have a history of fractures, did not have a family history of osteoporosis, were never treated for osteoporosis, and used a doctor's office or HMO for routine healthcare. Over the past year, most reported they had not seen a mental health professional in the past year. Only 13.0 % of subjects reported having no insurance.

There were 703 (10.3 %) who self-reported osteoporosis and 1024 (15.1 %) who had osteoporosis by DXA scan. Of those individuals with osteoporosis according to their DXA scan, only 287 (28.0 %) self-reported osteoporosis, whereas 737 (72.0 %) self-reported not having osteoporosis.

Table 1 Demographic, clinical, and access to healthcare characteristics of the study sample

Characteristics	Total sample (N = 7994)
Socio-demographics	
Age (50–65 years old)	4176 (52.2)
Gender (female)	3990 (49.9)
Race	
Non-Hispanic White	4284 (53.6)
Non-Hispanic Black	1615 (20.2)
Mexican–American	1182 (14.8)
Other/multiracial	913 (11.4)
Education	
High school or less	4570 (57.3)
Some college	1912 (24.0)
College graduate or more	1495 (18.7)
Marital status (married)	4776 (59.8)
Annual family income (<$55,000)	5137 (69.8)
Clinical characteristics	
Body mass index (kg/m^2)	
<25	1985 (25.4)
25 to <30	2813 (36.0)
≥30	3012 (38.6)
General health condition	
Excellent or very good	2713 (34.0)
Good or fair	4700 (58.8)
Poor	579 (7.2)
Alcohol consumption	
0 drinks/day	3206 (44.0)
<4 drinks/day	3522 (48.3)
≥4 drinks/day	562 (7.7)
Smoking status (smoker)	1313 (16.4)
Taken prednisone or cortisone daily	515 (6.5)
Arthritis	3624 (45.4)
Thyroid problem	1156 (14.5)
History of fracture	277 (3.5)
Family history of osteoporosis	833 (11.1)
Ever treated for osteoporosis	944 (11.8)
Seen mental health professional past year	471 (5.9)
Access to healthcare	
Type of routine healthcare place	
Clinic or health center	1473 (19.9)
Doctor's office or HMO	5519 (74.6)
Hospital	330 (4.4)
Some other place	80 (1.1)
Number of healthcare visits past year	
0–3 visits	3870 (48.5)
4–9 visits	2612 (32.7)
≥10 visits	1502 (18.8)
Type of health insurance	
Private or single plan	2351 (29.5)
Government	1862 (23.3)
Multiple plans	2726 (34.2)
No insurance	1039 (13.0)

The agreement statistics between self-reported osteoporosis diagnosis and examination results are presented in Table 2. For the total sample, chance-adjusted agreement or kappa and sensitivity were relatively poor. Specificity and NPV were good overall, while PPV was fair.

When comparing men and women, kappa was poor regardless of gender, but poorer among men. Additionally, sensitivity was relatively poor across both genders, while specificity and NPV were good. Specifically, sensitivity and PPV were lower among men (Table 2).

When stratified by age groups, kappa was poor in both age groups, but higher in older individuals than younger individuals. Sensitivity was poor across both age groups, but slightly higher among the older individuals. PPV was poorer in the younger individuals (Table 2).

Bivariate associations between agreement and potential-associated factors are described in Table 3. Results from logistic regression showed that before adjustment, subjects with agreement were more likely to be older, female, non-Hispanic White, Mexican–American, or some other race, single or not married, and a nondrinker or light drinker. Additionally, subjects more often had an annual family income less than $55,000, had a BMI less than 30 kg/m^2, had a poorer health status, had taken prednisone or cortisone daily, had arthritis, had a thyroid problem, had a history of fractures, had a family history of osteoporosis, had been treated for osteoporosis, had more than three healthcare visits in the past year, and had a government health insurance plan or multiple plans (Table 3).

Results for the adjusted model were displayed in Table 4. Of the variables chosen for inclusion in the final model, several factors were found to be significantly associated with agreement. More specifically, agreement was significantly associated with age, gender, race, BMI, self-reported general health condition, history of fractures, and osteoporosis treatment. In particular, older age, women, those who were non-Hispanic White, Mexican–American, or some other race, overweight or obese individuals, those who self-reported poorer overall health, those with a history of fracture, and those who had been treated with osteoporosis were associated with better agreement (Table 4).

Discussion

Self-report on health status provides important data in epidemiology and public health research. This study validated self-reported data using the available BMD data from a national, representative sample of mid-age and older adults. The principle of conclusions that can be drawn from this analysis relate to the agreement between self-reported prevalent diagnosis and BMD-supported diagnosis, together with factors that contributed to this agreement. The results of this study showed that only a small proportion of participants with osteoporosis defined by their BMD who actually reported having osteoporosis. This is reflected by a low sensitivity (28.0 %), fair PPV (40.8 %), and weak kappa statistic (0.24) across both gender and age groups. When individuals with a history of osteoporosis-related fractures were included in our definition of osteoporosis, regardless of BMD, there were no differences in the results since in our total sample there were only 32 individuals who reported a history of fractures but had normal BMD according to the DXA scan result. Our finding is consistent with previous studies conducted in different populations. For example, when analyzing data from a group of 1749 Australian subjects, Stuart et al. [4] reported a sensitivity of 33.6 %, PPV of 31.4 %, and a kappa statistic of 0.29. Cadarette et al. [5] reported a slightly higher agreement level (kappa = 0.42) between self-report and actual DXA results. However, their sample consisted of older women in the age group of 65–90, which was a population with higher risk of osteoporosis.

When post hoc analysis was conducted, we found that among those who self-reported osteoporosis besides the 40.8 % (n = 287) who actually had osteoporosis, 45.2 % (n = 318) had osteopenia using the diagnosis threshold described by Kanis et al. [14], and 13.9 % (n = 98) had normal BMD according to the DXA results. A possible explanation for those with osteopenia may be that patients were confused between the two terms as indicated by some previous reports [15], or healthcare providers were unable to effectively communicate with their patients about either condition to ensure patients understand their diagnosis [5,

Table 2 Agreement statistics between self-reported osteoporosis diagnosis and examination results by gender and age group

	Total sample	Gender		Age	
		Male	Female	50–65 years old	>65 years old
Kappa	0.24 (0.21–0.27)	0.07 (0.03–0.12)	0.23 (0.19–0.27)	0.13 (0.09–0.18)	0.28 (0.24–0.32)
Sensitivity	28.0 (25.3–30.8)	8.1 (4.7–11.5)	34.4 (31.0–37.7)	17.7 (13.7–21.7)	33.3 (29.7–36.8)
Specificity	92.8 (92.1–93.5)	97.4 (96.8–97.9)	87.1 (85.8–88.4)	94.1 (93.3–94.9)	91.0 (89.9–92.2)
PPV	40.8 (37.2–44.5)	19.1 (11.5–26.6)	44.7 (40.7–48.6)	23.7 (18.5–28.9)	50.7 (46.0–55.3)
NPV	87.9 (87.1–88.7)	93.2 (92.4–94.1)	81.4 (79.9–82.8)	91.7 (90.7–92.6)	83.1 (81.7–84.5)

PPV positive predictive value, *NPV* negative predictive value

Table 3 Unadjusted logistic regression models showing the relationship between socio-demographic, clinical, and access to healthcare factors and agreement of self-reported osteoporosis diagnosis and exam results

Variable	Odds ratio	95 % confidence interval	
Socio-demographics			
Age			
50–65 years old	Reference		
>65 years old	4.25*	3.20	5.66
Gender			
Male	Reference		
Female	14.27*	9.04	22.53
Race			
Non-Hispanic Black	Reference		
Non-Hispanic White	4.29*	2.60	7.07
Mexican–American	3.63*	2.06	6.39
Other/multiracial	4.20*	2.36	7.47
Education			
High school or less	Reference		
Some college	0.86	0.64	1.14
College graduate or more	0.73	0.52	1.03
Marital status			
Married	Reference		
Not Married	1.69*	1.33	2.13
Annual family income			
≥$55,000	Reference		
<$55,000	2.14*	1.54	2.96
Clinical characteristics			
Body mass index (kg/m^2)			
≥30	Reference		
<25	4.41*	3.17	6.15
25 to <30	2.28*	1.61	3.21
General health condition			
Poor	Reference		
Excellent or very good	0.58*	0.38	0.89
Good or fair	0.70	0.47	1.04
Alcohol consumption			
≥4 drinks/day	Reference		
0 drinks/day	6.25*	2.56	15.28
<4 drinks/day	3.22*	1.31	7.95
Smoking status			
Smoker	Reference		
Nonsmoker	1.38	0.97	1.97
Taken prednisone or cortisone daily			
No	Reference		
Yes	2.29*	1.60	3.27
Arthritis			
No	Reference		
Yes	2.13*	1.67	2.72

Table 3 continued

Variable	Odds ratio	95 % confidence interval	
Thyroid problem			
No	Reference		
Yes	2.27*	1.73	2.97
History of fracture			
No	Reference		
Yes	5.15*	3.60	7.37
Family history of osteoporosis			
No	Reference		
Yes	2.28*	1.68	3.10
Ever treated for osteoporosis			
No	Reference		
Yes	42.47*	31.28	57.67
Seen mental health professional past year			
No	Reference		
Yes	1.01	0.61	1.66
Access to healthcare			
Type of routine healthcare place			
Clinic or health center	Reference		
Doctor's office or HMO	1.26	0.91	1.75
Hospital	1.30	0.69	2.44
Some other place	1.23	0.38	4.06
Number of healthcare visits past year			
0–3 visits	Reference		
4–9 visits	1.61*	1.23	2.12
>9 visits	1.87*	1.38	2.54
Type of health insurance			
No Insurance	Reference		
Private or single plan	0.71	0.41	1.23
Government	2.13*	1.31	3.46
Multiple plans	2.91*	1.83	4.61

* Statistical significance ($p < 0.05$)

16]. On the other hand, individuals with normal BMD may have self-reported osteoporosis due to several reasons. For example, when verifying with the prescription data, we found that out of the 147 subjects who had normal BMD, but identified themselves as having osteoporosis, 14 subjects with no history of fractures were actually under bisphosphonates treatment for osteoporosis, demonstrating a potential lack of knowledge about the treatment. Additionally, the lack of knowledge about the disease might explain the reason why individuals had normal BMD, but identified themselves as having osteoporosis. Further scrutiny of the data showed that 88.8 % of these subjects had arthritis which is often confused with osteoporosis [17]. However, without an

Table 4 Adjusted logistic regression model showing the relationship between socio-demographic and clinical factors and agreement of self-reported osteoporosis diagnosis and exam results

Variable	Odds ratio	95 % confidence interval	
Socio-demographics			
Age			
50–65 years old	Reference		
>65 years old	3.03*	2.20	4.18
Gender			
Male	Reference		
Female	4.90*	2.96	8.13
Race			
Non-Hispanic Black	Reference		
Non-Hispanic White	1.92*	1.11	3.32
Mexican–American	2.63*	1.40	4.91
Other/multiracial	2.87*	1.52	5.41
Clinical characteristics			
Body mass index (kg/m^2)			
≥30	Reference		
<25	3.33*	2.28	4.88
25 to <30	2.31*	1.57	3.40
General health condition			
Poor	Reference		
Excellent or very good	0.40*	0.23	0.68
Good or fair	0.57*	0.35	0.93
History of fracture			
No	Reference		
Yes	1.75*	1.12	2.72
Ever treated for osteoporosis			
No	Reference		
Yes	20.52*	14.77	28.51

* Statistical significance ($p < 0.05$)

assessment of this knowledge or health literacy in general, it is not possible to explain further on the discrepancy.

Few past studies have examined the influence of socio-demographic factors on the agreement between self-report of osteoporosis and BMD data. Our study showed that this agreement could be confounded by demographic, socioeconomic, and clinical factors. When stratified by gender, a higher sensitivity was observed in women (34.4 %) comparing to men (8.1 %). Logistic regression models also confirmed that women are 4.9 times more likely to provide accurate self-reports, comparing to men. A possible explanation could be the fact that osteoporosis has always been known more as a woman's health problem, as pointed out by McLeod and Johnson [18]. For example, in this particular study 17.9 % of women identified themselves as having osteoporosis comparing to 3.0 % of men. Because of this popular belief, women might tend to be more cognizant

of their bone health comparing to men, although there has been a body of research focusing on osteoporosis in men [19–25].

While the literature on self-reported diagnosis in other health conditions indicated that aging is significantly related with poor agreement [7], in this work we found that older participants were more likely to provide true positive self-reports comparing to mid-age participants. To the best of our knowledge, very few studies on osteoporosis have looked at the contribution of age in the accuracy of self-report. The only study we could find that looked at age as a contributing factor was one that examined the agreement between self-report osteoporosis and medication claims in a cohort of women only. The authors found that the agreement was poor in women of age 56–61 years old and moderate in women of age 79–84 years old, which is somewhat in line with our results [8].

Other characteristics that were significantly associated with true positive self-reports included race, BMI, health condition, history of fractures, and treatment of osteoporosis. The odds of correctly self-reporting osteoporosis are higher in non-Hispanic White, Mexican–American, and other or multiracial comparing to non-Hispanic Black individuals, individuals with lower BMI (normal and overweigh) comparing obese, individuals with poor health condition comparing those in very good/excellent health condition, and in individuals who had history of fractures and have had osteoporosis treatment comparing to those who have not. Contrary to our expectation, we did not find any significant association between self-report agreement and common factors that could contribute to health literacy or knowledge of the disease such as education, income, access to healthcare, and number of healthcare visits per year.

This study offered some strengths. First, the NHANES provided a large, national representative sample with a high response rate. The survey was conducted by trained household interviewers administered in the participants' home using a computer-assisted personal interview system. There have been evidences that interviewing techniques are important to the validity of self-report diagnosis. Second, NHANES data include rich sources of information such as demographic, socioeconomic, lifestyle, health condition, and medical records, all are ideal for the design of this study. Third, the validation of self-report data in our analysis was determined by BMD measurement using DXA, a gold standard for the diagnosis of osteoporosis. NHANES examination results are the largest publicly available dataset in the USA with recorded bone measurements and appropriate quality control and calibrations. Finally, while most previous studies on similar topics only focused on women, our analysis extended the hypothesis testing to men in response to findings concerning osteoporosis in men reported in the literature.

The current study is also subject to some limitations. While our analysis compared the actual DXA results with patient acknowledgement of having the disease, many factors that might affect this correlation were not captured in the data, such as patient knowledge of the disease or how effective their physicians communicated with them once they had osteoporosis. Our study also could not address where the inconsistency between the two sources of data came from or how information was lost. The BMD values were collected only at one point in time in the NHANES data and might be subject to measurement errors. Unfortunately, the NHANES survey does not include questions for subjects to self-report osteopenia. The over-reporting of osteoporosis by participants may have been significantly affected by this. Finally, due to the retrospective nature of the data, no causal effect should be implied from the concluding results.

In conclusion, the results of this study suggested that there is a poor agreement between self-reported osteoporosis and BMD-defined diagnosis. Factors that are significantly associated with agreement were identified. Despite some limitations, to the best of our knowledge, this study is the first analysis that examined the concordance of self-reported and DXA results on such a broad range of conditions and time in a US population.

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