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The prevalence of previously diagnosed and undiagnosed psoriasis in US adults: Results from NHANES 2003–2004

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Abstract

Background—Psoriasis is a predictor of morbidity. It is important to determine the extent to which psoriasis remains undiagnosed.

Objective—To determine the prevalence of psoriasis

Methods—Cross-sectional study using the National Health and Nutrition Exam Survey 2003–2004.

Results—The prevalence of diagnosed psoriasis was 3.15% (95% CI 2.18, 4.53), corresponding to 5 million adults. The prevalence of undiagnosed active psoriasis by conservative estimate was 0.4% (95% CI 0.19, 0.82) corresponding to approximately 600,000 US adults. Undiagnosed patients had a trend towards being more likely to be male, non white, less educated and unmarried compared to patients who had received a diagnosis.

Limitations—The method for determining the presence of psoriasis had limited ability to detect mild disease and only fair inter-rater agreement.

Conclusion—Over 5 million adults have been diagnosed with psoriasis. A large number have undiagnosed psoriasis and there are important disparities which may be associated with not receiving medical attention.

INTRODUCTION

Psoriasis is a chronic, inflammatory disease of the skin and joints that negatively impacts health-related quality of life. More recent data has also demonstrated that psoriasis, particularly when severe, is associated with metabolic disorders, obesity, excess mortality, and may be an independent risk factor for developing atherosclerosis, myocardial infarction,

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and stroke^{1–6}. The treatment paradigm of psoriasis is undergoing a revolution with the recent approval of multiple systemic psoriasis treatments and the development of consensus statements which have broadened recommendations for which patients may qualify for systemic therapy^{7, 8}. Given these recent advances, it is important to understand how many patients suffer from psoriasis and which patients have disease that has substantial severity and/or impact on quality of life to warrant systemic therapy. Furthermore, since psoriasis is increasingly being recognized to be a predictor of current and future morbidities, it is important to determine the extent to which psoriasis remains undiagnosed in the general population.

Previous estimates of the prevalence of psoriasis in various locations throughout the world have ranged from 0.6% to 4.8%^{9–26}. These studies have varied in source population studied (e.g. various ages, general population-based vs. clinic based) definition of prevalence (point vs. period vs. lifetime), and definition of psoriasis (e.g. self report, vs. physician diagnosed). Two population-based studies in the continental US of adults have found a prevalence of psoriasis of 2.2%^{24, 27} and 2.6%⁹ based on patient report of a physician diagnosis attained by telephone and mail questionnaire, respectively. This approach may underestimate the true prevalence of disease because a significant portion of patients with psoriasis may not seek medical care and therefore be unaware of their diagnosis. The 1971–74 Health and Nutrition Examination Survey of persons 1–74 years of age found a point prevalence of psoriasis of 1.4% based on physician examination¹⁰. This study did not evaluate whether a patient had ever had psoriasis in the past and therefore may underestimate the prevalence of psoriasis as the disease may be in remission due to treatment, seasonal changes, or natural history⁹.

A more comprehensive method of assessing the prevalence of psoriasis is needed in order to capture psoriasis patients who are aware of their diagnosis as well as those who may remain undiagnosed. To further investigate the prevalence of psoriasis in the general US population we examined data from the National Health and Nutrition Examination Survey (NHANES) (2003–2004) which is unique in that it contains both information ascertained by patient report and physician exam, and therefore can be used to determine the prevalence of psoriasis in patients who are aware of their diagnosis as well as the prevalence of psoriasis in patients with active yet previously undiagnosed psoriasis.

METHODS

Study Design

We investigated the prevalence of psoriasis by analyzing data from the National Health and Nutrition Examination Survey (NHANES) in the United States from 2003–2004. The study was approved by the National Center for Health Statistics (NCHS) institutional review board and all subjects gave informed consent. NHANES is an ongoing population based, cross-sectional study which is designed to assess the health and nutritional status of people living in the United States. It is unique in that it combines interviews and physical examinations and the purpose of the NHANES initiative is to determine the prevalence of major diseases and risk factors for diseases in the United States. NHANES data is collected in two year cycles using a continuous stratified sampling technique. The first step is for participants to complete an interviewer-administered questionnaire. Physical exams are conducted within

1–2 weeks of the in-home interview in specially designed and equipped Mobile Examination Centers (MEC). The survey team consists of a physician, medical and health technicians and dietary and health interviewers who are extensively trained. The prevalence of psoriasis was determined by patient interview as well as examination of standardized clinical photographs by two dermatologists.

Study Population

This study uses a subset of the NHANES survey from 2003–2004 which is representative of the non-institutionalized United States civilian population aged 20–59 which was selected using a complex, multistage, stratified sampling design. African Americans, Mexican Americans and low income white Americans have been over sampled to increase the accuracy and precision of estimates of health status indicators for these population subgroups. The sample weights for NHANES 2003–2004 reflect the unequal probabilities of selection, non-response adjustments and adjustments to independent population controls and sampling adjustments are made during statistical analysis.

Definition of psoriasis

The prevalence of psoriasis was defined by two methods. The prevalence of previously diagnosed psoriasis was determined by interviewer-assisted questionnaire. A response of “yes” when asked “Have you ever been told by a health care provider that you had psoriasis?” was classified in our study as having psoriasis. This self-report method of ascertaining the prevalence of psoriasis has been well accepted in numerous epidemiological studies of psoriasis^{9, 15, 19, 24, 27}.

The presence of psoriasis was also determined by review of standardized clinical photographs by two dermatologists. The data collection method consisted of taking standardized images of potentially affected areas of the skin during the MEC examination using a digital camera. Sites included the back, lower extremities, hands, and arms as follows: one image of the back that includes the elbows; one image of the left upper inner arm; one image of the dorsal surface of both hands combined with an image of the front lower legs; and one image of the palm of both hands combined with an image of the back and lower legs. Prior to concluding the exam, images were checked for quality. The images were then transferred to a DVD and given to two independent dermatologists for analysis.

A diagnosis of psoriasis by both dermatologists in a patient who reported no history of diagnosis of psoriasis by questionnaire was used as our conservative definition of “undiagnosed active” psoriasis. A diagnosis by at least one dermatologist in a patient who reported no history of diagnosis of psoriasis by questionnaire was used as our less conservative definition of “undiagnosed active” psoriasis.

Definition of covariates

Those patients who reported a previous diagnosis of psoriasis by questionnaire were asked additional questions regarding the extent of their psoriasis as well as the impact that psoriasis has on their daily lives. Patients were asked, “Do you currently have little or no psoriasis, only a few patches that could be covered by one or two palms of your hand,

scattered patches that could be covered between 3 and 10 palms of your hand, or extensive psoriasis covering large areas of the body that would require more than 10 palms of your hand.” By convention, the palm of the hand is estimated to be approximately 1% body surface area (BSA) and therefore we present these categories as little/no psoriasis, 1–2% BSA, 3–10% BSA, and >10% BSA, respectively²⁸. For additional and logistic regression analyses, psoriasis severity categories were dichotomized into mild (<3%) and moderate to severe (≥3%). Patients were asked to answer the question “On a scale of 1 to 10 how much of a problem has your psoriasis been in your everyday life where 1 means no problem at all and 10 means a very large problem.” Ordinal categories were created for additional analyses in a manner identical to previously published work (1–3: no or little impact, 4–7: a problem, 8–10: a large problem)²⁴.

Additional covariate information for all patients such as age, gender, race, education, income, health insurance and marital status were determined by questionnaire. Education was dichotomized into greater than high school education or not. Income was dichotomized into less than or equal to a median income level of \$35,000–\$44,999 or greater and marital status was dichotomized into married or not married. In descriptive statistics, the prevalence of race was reported based on questionnaire categories (Caucasian, Black, Hispanic, Other) but for logistic regression was dichotomized into white or non-white.

Other variables of interest such as frequency of physician visits, current smoking, alcohol use, depression and anxiety screening were not used because of a high proportion of missing data. In order to maintain quality analyses, only covariates for which data was recorded in at least 90% of patients was included.

Statistical methods

All statistical analyses were performed using survey commands of STATA to incorporate sample weights and adjust for clusters and strata of the complex sample design (Version 10, STATA Corporation, College Station, TX). The prevalence of psoriasis was determined by responses to the dermatological questionnaire as well as dermatological clinical evaluation. Prevalence and covariate data were reported as percentages with 95% confidence intervals using the survey tabulate command in STATA. Odds ratios with 95% confidence intervals were calculated using survey logistic regression for both unadjusted and adjusted (for age and gender) analyses. Quality of life data were analyzed using logistic regression and linear regression. Agreement about the presence of psoriasis on the clinical photographs was assessed via the kappa statistic. All p values reported are two-sided.

RESULTS

The dermatologic interview and exam were only administered to subjects age 20–59 and represent a subset of the total NHANES data which includes all ages. An unweighted sample size of 4,163 people age 20–59 were screened, 3,140 of whom participated in questionnaire-based interviews. A total of 2,984 of the interviewed subjects had non missing psoriasis questionnaire data and this was the cohort used to calculate prevalence estimates of psoriasis. Data from dermatologist review of clinical photographs was available for 90% of patients in this cohort. The raw data includes 73 patients with psoriasis as determined by

self-report of a health care provider diagnosis on questionnaire. Upon examination of standardized photographs, 84 patients were determined to have active psoriasis by at least one dermatologist, 66 of whom by self report had never received a prior diagnosis of psoriasis by a health care provider. Among the 73 patients who reported a prior health care provider diagnosis of psoriasis, the presence of psoriasis, based on review of the standardized clinical photographs, could only be confirmed by at least one of two dermatologists in 18 patients. Confirmation of active psoriasis was strongly dependent upon patient self report of skin severity. For example, the odds of one or both evaluators confirming psoriasis was 11.71 (95%CI 4.03, 33.98, $p<0.001$) and 9.71 (95%CI 1.77, 53.34, $p=0.01$), respectively for patients with self reported BSA $\geq 3\%$ compared to patients with no to mild psoriasis by self report (e.g. BSA $< 3\%$). Agreement between the two dermatologists on the presence of psoriasis for all subjects evaluated was only fair²⁹ (Kappa 0.36, $p<0.001$) and both dermatologists agreed only 17% of the time in previously undiagnosed individuals. However, agreement between the two dermatologists among photos of subjects who self reported the presence of psoriasis via questionnaire was moderate²⁹ (Kappa 0.54, $p<0.001$) and agreement among subjects with the most extensive disease ($>10\%$ BSA) was perfect (Kappa 1.0, $p=0.02$).

To determine prevalence estimates and measures of association, the raw data were adjusted for the sampling technique (Table 1). The prevalence of psoriasis based on patient report of a health care provider diagnosis of the disease was similar in men and woman and is estimated to be 3.15% (95% CI 2.18, 4.53) of the US population age 20–59. The prevalence of undiagnosed active psoriasis is estimated to be 0.4% (95% CI 0.19, 0.82) based on a conservative definition (e.g. both evaluators needed to confirm the presence of psoriasis). The prevalence of undiagnosed active psoriasis based on a less conservative definition (e.g. at least one of the two evaluators needed to confirm the presence of psoriasis) was 2.28% (95%CI, 1.47, 3.50) of the US population age 20–59.

Table 1 also summarizes characteristics of patients with previously diagnosed psoriasis compared to patients with undiagnosed active psoriasis. Subsequent analyses were conducted to determine which factors were associated with not receiving a previous diagnosis of psoriasis. Although not statistically significant due to a small sample size, regression analysis adjusted for age and sex showed a trend towards a greater likelihood of being male (OR: 5.72, 95%CI 0.49, 67.35), non white (OR: 1.34, 95%CI 0.20, 8.83), less educated (OR: 3.78, 95%CI 0.64, 22.37) and not married (OR: 1.70, 95%CI 0.26, 11.05) in patients with undiagnosed active psoriasis confirmed by both dermatologists compared to patients with a previous diagnosis of psoriasis. Patients with undiagnosed psoriasis based on the less conservative definition were more likely to be male (OR 4.29, 95%CI, 2.34, 7.87), non white (OR 2.12, 95%CI, 1.00, 4.48), have a lower household income (OR 2.46 95%CI 1.02, 5.95), be less educated (OR 3.51, 95%CI, 1.39, 8.88) and not married (OR 2.65, 95%CI 1.39, 5.07) compared to patients who had received a diagnosis. Health insurance status was not associated with having newly diagnosed psoriasis (OR 1.83, 95%CI, 0.73, 4.61).

Patients with a history of health care provider-diagnosed psoriasis were asked to provide information on the extent of their psoriasis as well as how psoriasis impacts their daily life.

Psoriasis impact on daily life was scored from 1–10 where 1 indicates no impact and 10 indicates severe impact (Table 2). When analyzing the extent of psoriasis on daily life, previously established categories were applied (1–3; little or no problem, 4–7; a problem, 8–10; a large problem)²⁴. Over half (56.66%) of all psoriasis patients with a previous diagnosis reported that psoriasis was a little or no problem in their daily lives while 18.44% reported that it was a problem and 24.91% that it was a large problem. It is estimated that 83.37% of the previously diagnosed psoriasis population has limited skin disease (<3% BSA) while 16.63% are estimated to suffer from more moderate to severe disease (≥3% BSA). After adjusting for age and gender, the extent to which psoriasis impacts daily life was associated with psoriasis severity ($p < 0.001$ for trend). For example, 16% of patients with mild psoriasis rated it as a large problem whereas 72% of moderate to severe psoriasis patients rated it as a large problem.

DISCUSSION

The unique design of the NHANES 2003–2004 in which the prevalence of psoriasis was measured by both patient self-report of a prior health care provider diagnosis as well as by review of clinical photographs provides important confirmation of previous epidemiological studies as well as novel findings. First, the prevalence of self report of a health care provider diagnosis of psoriasis is statistically similar to previous estimates in the US adult population using comparable methods^{9, 24}. Second, this study confirms that a substantial number of psoriasis patients suffer from disease which is severe enough to warrant systemic therapy based on current consensus statements^{7, 8}. For example, about 17% have moderate to severe psoriasis based on body surface area estimates, and 25% of patients rate psoriasis as a large problem in everyday life. Furthermore, we determined that by conservative estimates approximately 0.4% (2.28% based on a less strict definition) of the general population ages 20–59 have undiagnosed, clinically active psoriasis. Importantly, our analyses demonstrate that significant disparities may exist among psoriasis patients in terms of the likelihood that they have been previously diagnosed by a health care provider. In particular, people with undiagnosed active psoriasis may be more likely to be male, unmarried, non-white, and have less education.

Applying these prevalence estimates to the population at the time these data were collected, it is estimated that approximately 5 million people age 20–59 have been previously diagnosed with psoriasis, and that despite having active disease, an additional 600,000 (conservative estimate) to 3.6 million people have psoriasis but remain undiagnosed. Furthermore, we estimate that 1.4 million patients age 20–59 have moderate to severe disease and that 2.1 million consider psoriasis to be a large problem in daily life.

A particular strength of this study is that NHANES participants are selected in a manner that is representative of the general US population. In addition, interviews and exams are conducted on site at people's homes and participation rates are favorable to other published reports of the prevalence of psoriasis^{9, 30}. As with any study, there are important limitations to consider. As NHANES interviewers and examiners were unaware of our hypothesis to be tested, it is unlikely that any misclassification of covariates measured was directional (i.e., that misclassification was more likely to occur in subjects who had psoriasis than those who

did not), and therefore any such misclassification would bias our findings towards the null. Furthermore, the sample size of this study was not large enough to perform analyses in certain sub-populations and many estimates were subject to imprecision (e.g. wide confidence intervals).

A particular challenge to conducting epidemiological studies in psoriasis is that there is no universally agreed upon gold standard case definition of psoriasis which is readily applied in the setting of a broadly representative population-based study. Patient interview (questionnaire) data are commonly used, but are based on self-reports and are therefore subject to errors such as recall bias (forgetting a previous diagnosis or recalling a diagnosis which did not occur), misunderstanding of the question, inability to identify cases which have not received a medical diagnosis, and various other factors which can result in an under or over estimate of the prevalence of psoriasis. Nevertheless, patient recall of chronic medical conditions has generally been shown to be accurate and use of self-report of a psoriasis diagnosis has been well accepted in previous epidemiological studies^{9, 24, 31, 32}.

To address the limitation of self-report of a physician diagnosis of psoriasis, NHANES also evaluated prevalence of psoriasis based on review of standardized clinical photographs by two dermatologists. As a tool to detect psoriasis in the general population, this method was limited by only fair agreement about the presence of psoriasis in the standardized photographs by the two reviewing dermatologists. The results of this study also indicate that standardized photographs are significantly less likely to detect psoriasis which affects a limited body surface area (e.g. 2%). This limitation is problematic given that the overwhelming majority of psoriasis cases are mild or potentially in remission in the general population as demonstrated by the current and previous studies²⁴. Furthermore, in the NHANES study anatomic areas such as the chest, abdomen, feet, scalp, buttock and groin were not photographed which could also result in not identifying cases of psoriasis. Several factors such as disease that is limited, in remission or located on anatomical sites not photographed, may lead to an underestimate of the true prevalence of undiagnosed psoriasis based on the NHANES data. Review of standardized photographs was much more likely to confirm psoriasis in those with higher self-reported body surface area of involvement and agreement was excellent in those with the most severe psoriasis (e.g. BSA 10%); suggesting that photography may be a valid method for detecting severe disease in the general population.

In conclusion, this study demonstrates that psoriasis is common and is associated with a substantial health burden in a significant percentage of cases. Importantly, our results suggest that a large number of patients with active psoriasis remain undiagnosed and that a variety of socioeconomic disparities may explain why psoriasis may be undiagnosed. Additional studies are needed to better define the prevalence of undiagnosed psoriasis and to determine what barriers exist which prevent these patients from receiving medical care for this important disease.

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Table 1

Summary statistics of psoriasis patients in the US population ages 20–59.

	No Psoriasis	Psoriasis		
		History of health care provider diagnosis	Undiagnosed active psoriasis-conservative estimate ¹	Undiagnosed active psoriasis less conservative estimate ²
Psoriasis prevalence (95%CI)	NA			
Overall		3.15% (2.18, 4.53)	0.40% (0.19, 0.82)	2.28% (1.47, 3.50)
Women		1.62% (1.02, 2.55)		0.48% (0.22, 1.03)
Men		1.53% (0.97, 2.40)		1.8% (1.15, 2.8)
Gender % male (95%CI)	49.03% (47.69, 50.36)	48.61% (35.54, 61.86)	82.31% (25.62, 98.43)	79.1% (63.99, 88.96)
Mean age (95%CI)	38.91 (38.10, 39.72)	41.11 (38.80, 43.42)	44.06 (34.58, 53.54)	41.69 (38.74, 44.64)
Race				
(% White)	68.79%	81.61%	79.94%	70.01%
(% Black)	12.16%	7.96%	12.19%	16.76%
(% Hispanic)	13.29%	6.53%	7.87%	4.44%
(% Other)	5.76%	3.9%	0	8.79%
Income median % ³ (95%CI)	43.91% (39.49, 48.43)	37.37% (28.24, 47.49)	26.89% (4.78, 72.94)	51.63% (36.83, 66.16)
No advanced (post-high school) education % (95%CI)	42.59% (40.38, 44.83)	29.51% (19.58, 41.86)	57.17% (25.50, 83.89)	56.85% (45.58, 67.45)
Not Married (95%CI)	43.86% (40.45, 47.32)	31.79% (23.01, 42.09)	37.97% (11.62, 74.03)	47.10% (29.19, 65.79)
No health insurance (95%CI)	22.59% (20.44, 24.89)	16.15% (9.19, 26.83)	0	27.16% (14.63, 44.79)

Psoriasis patients with a history of health care provider diagnosis and patients with undiagnosed active psoriasis are compared to patients without psoriasis.

¹The conservative estimate of undiagnosed active psoriasis is determined by agreement of psoriasis by both dermatologists upon review of standardized photographs in a patient who reported no previous diagnosis of psoriasis by a health care provider

²Undiagnosed active psoriasis by less conservative estimate is determined by at least one dermatologist upon review of standardized photographs in a patient who reported no previous diagnosis of psoriasis by a health care provider

³Median income is \$35,000 to \$44,999

Table 2

Extent of psoriasis severity and impact on daily life in patients with history of a health care provider diagnosis of psoriasis.

	Mild Psoriasis		Moderate to Severe Psoriasis	
	Little/no Psoriasis	1–2% BSA Psoriasis	3–10% BSA Psoriasis	>10% BSA Psoriasis
Proportion of psoriasis patients	51.59%	31.68%	11.38%	5.25%
Mean psoriasis impact on daily life (95%CI)	3.22 (2.37, 4.07)	4.11 (2.97, 5.25)	7.32 (5.31, 9.32)	10 (10, 10)

83.37% of psoriasis patients with a history of physician diagnosis had mild psoriasis (little/no to 1–2% BSA) while 16.63% had moderate to severe disease (3% or greater BSA). Mean psoriasis impact on daily life score increased with increasing psoriasis severity. BSA = body surface area.