Letter

Research letter

Prevalence of prurigo nodularis in the United States of America: A retrospective database analysis

To the Editor: Prurigo nodularis (PN) is a chronic disease characterized by multiple intensely pruriginous nodules and papules and presents significant challenges for treatment and quality of life.[1] Prevalence data are currently scarce,[1] although recent efforts evaluating real-world United States (US) PN prevalence have been made.[2]

We evaluated International Classification of Diseases (ICD)-9 data from 2010 and 2015 from the National Ambulatory Medical Care Survey, and ICD-10 data (L28.1) from Medicare (2017) and the US claims databases Symphony Health (2017) and LexisNexis PxDx (2017/2018) to calculate the treatment prevalence based on estimated population size and diagnostic codes for medical claims of unique patients. We used the ICD-9 code of 698.3 for PN; given that this code is used more broadly, we conservatively estimated that 33% of encounters coded as 698.3 actually represented PN.

The estimated PN prevalence ranged from 36.7 to 148.3 per 100,000 population (see Table I).[3] A higher estimate reflects a predominantly elderly Medicare population (see Table II for age-stratified data). Of note, the PN prevalence, based on National Ambulatory Medical Care Survey ICD-9 data, increased by 27% from 2010 to 2015. Estimates based on the more precise, recent ICD-10 coding suggest a prevalence of 36.7-43.9 per 100,000 population.

The potential limitations are as follows: ICD-9 has no PN-specific code, and ICD-10 has 2 PN codes with unknown coding accuracy.[4,5]

The comprehensive, projected ICD-10 data from LexisNexis PxDx, which includes 165 million unique inpatient and outpatient visits, suggest that approximately 120,000 people were diagnosed with and/or treated for PN over a 12-month period (October 2017-September 2018). Despite meeting the Orphan Drug Act 1983 definition of an orphan disease (<200,000 people affected), PN, nevertheless, has a substantial case burden in the United States of America. Assuming shifts in age distribution and a better disease definition, the data may indicate an improved diagnosis of PN over the past decade. Additional clinical research, improved disease awareness, and clinical coding optimization will further improve the accuracy of PN diagnoses. Coding optimization is especially critical because data-entry errors are a source of misclassification in database analyses. Knowledge of such errors and their adjustment is helpful in improving the understanding of the disease's epidemiology.

This retrospective database analysis estimates the PN prevalence in the United States of America to range from 36.7 to 43.9 per 100,000 population based on the ICD-10 coding for L28.1 (148.3 per 100,000 for the predominantly elderly Medicare population) and up to 52.2 per 100,000 population using the less accurate ICD-9 coding. In a recent analysis of a claims database providing services to 24 million enrollees, Huang et al[2] identified 7095 PN cases in individuals aged 18-64 years and estimated the US prevalence to be 87,634 or 72 per 100,000 population in this demographic. Their analysis probably underestimated the true size of the 18-64—year demographic; moreover, it relied on commercial claims from a single small database, which limited generalizability and excluded the >65-year demographic.

Together, these data represent recent efforts at estimating the PN prevalence in the general US population. Future challenges will be to expand the National Ambulatory Medical Care Survey data to include ICD-10 coding and validate the coding accuracy of this and other databases.

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Table I. Estimated prevalence of PN in USA

	NAMCS ICD-9			US claims database ICD-10*	
	2010	2015	Medicare 2017 ICD-10	LexisNexis PxDx 2017/2018	Symphony Health 2017
Estimated total population, n	314 million	321 million	56.3 million	326 million	
Estimated PN population, n†	129,029	167,709	83,500	119,553	143,038
Prevalence, %	0.041	0.052	0.148	0.037	0.044
Prevalence per 100,000 population, n	41.1	52.2	148.3	36.7	43.9

ICD-9, International Classification of Diseases, Ninth Revision; *ICD-10*, International Classification of Diseases, Tenth Revision; *NAMCS*, National Ambulatory Medical Care Survey; *PN*, prurigo nodularis; *USA*, United States of America.
*Uninsured rates in 2017 and 2018 were 7.9% and 8.5%, respectively.
†Realistic case scenario.

Table II. Estimated prevalence of PN in USA stratified by age*

		Age group (years)				
		<15	15-24	25-44	45-64	>65
2010 NAMCS ICD-9†	n	7949	3717	24,923	32,844	59,596
	%	6.2	2.9	19.3	25.5	46.2
2015 NAMCS ICD-9†	n	2919	16,914	38,076	30,164	79,635
	%	1.7	10.1	22.7	18.0	47.5

ICD-9, International Classification of Diseases, Ninth Revision; *NAMCS*, National Ambulatory Medical Care Survey; *PN*, prurigo nodularis; *USA*, United States of America.
*Age-stratified data were only available for the NAMCS ICD-9 codes.
†Realistic case scenario.

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