Prevalence of Prurigo Nodularis in the United States: Findings of a Retrospective Database Analysis

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INTRODUCTION

- Prurigo nodularis (PN), a chronic condition characterized by multiple hyperkeratotic, intensely pruritic skin nodules and papules, presents significant challenges for treatment and quality of life.[1]
- Prevalence data are currently scarce,[2] although recent efforts evaluating real-world US PN prevalence have been made.[3]
- Use of International Classification of Diseases (ICD) coding presents an opportunity to evaluate PN prevalence.
- Potential pitfalls include: ICD, Ninth Revision (ICD-9) has no PN-specific code and PN-specific ICD-10-L28.1 diagnostic and coding accuracy is unknown.[4]
- A second ICD-10 code (L28.2) collects other prurigo diagnoses, but the relative prevalence of prurigo cases is unknown.

METHODS

- We evaluated National Ambulatory Medical Care Survey (NAMCS) ICD-9 2010 and 2015 data and ICD-10 data from Medicare 2017 and the US claims databases Symphony Health 2017 and 2017/2018 LexisNexis PxDx to calculate prevalence based on estimated population size and diagnosis codes for medical claims of unique patients.
- ICD-9 data assumed maximum case (all 698.2 and 698.3 diagnoses are PN) and realistic case (all PN diagnoses are confined to 698.3, one-third of all diagnoses in 698.3 are PN) scenarios.

RESULTS

- An estimated PN prevalence ranging from 36.7 to 148.3 per 100,000 population was seen (Table).
- The higher estimate reflects a predominantly elderly Medicare population.
- PN prevalence increased by 46% from 2010 to 2015, based on NAMCS ICD-9 data.
- Estimates based on more precise and recent ICD-10 coding suggest a prevalence of 36.7– 43.9 per 100,000 population.

DISCUSSION

- Comprehensive, projected ICD-10 data from LexisNexis PxDx, which includes 165 million unique patients and covers inpatient, outpatient, and office visits, suggest that approximately 120,000 people were diagnosed and/or treated for PN over a 12-month period (ending September 2018).
- Although meeting the Orphan Drug Act 1983 definition of an orphan disease (< 200,000 people affected), PN nevertheless has a substantial case burden in the USA.

DISCUSSION (cont.)

- Age and sex distribution data are currently unavailable. However, assuming shifts in age distribution, better disease definition and diagnosis, and increased awareness, the data suggest improved diagnosis of PN over the past decade.
- Increased clinical activities, including research, improved disease awareness, and clinical coding optimization, will further improve disease diagnosis.
- Clinical coding optimization is especially important in the present context since data entry errors are a source of confounding in database analyses.
- Knowledge of such errors and their adjustment are helpful in improving the understanding of disease epidemiology.
- Since coding is used primarily for billing and hospital reimbursement purposes, analyses of disease prevalence constitute a secondary purpose.
- Furthermore, potential misuse, i.e. recording only diagnoses that lead to reimbursement or "up-coding" in order to increase reimbursement, might occur.

CONCLUSION

- This retrospective database analysis estimates the prevalence of PN in the US to range from 36.7 to 43.9 per 100,000 population based on the new ICD-10 coding (and 148.3 per 100,000 for the predominantly elderly Medicare population), and higher rates up to 60.2 per 100,000 population using the less accurate ICD-9 coding.
- The data, including data presented in 2019, represent valuable first efforts at estimating PN prevalence in the general US population.
- Future challenges will be to expand NAMCS data to include ICD-10 coding and to determine the diagnostic and coding accuracy of this and other databases.

Table. Estimated prevalence of prurigo nodularis in the United States

	NAMCS ICD-9		Medicare 2017 ICD-10	US claims databases ICD-10	
	2010	2015		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[a]	193,276[a]	83,500	119,553	143,038
Prevalence as percentage of population	0.041%	0.060%	0.148%	0.037%	0.044%
Prevalence per 100,000 population, n	41.1	60.2	148.3	36.7	43.9

[a]Realistic case scenario. 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.

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