

Epidemiology and patient journey in inclusion body myositis: A machine learning methodology applied to claims data in the United States

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Introduction

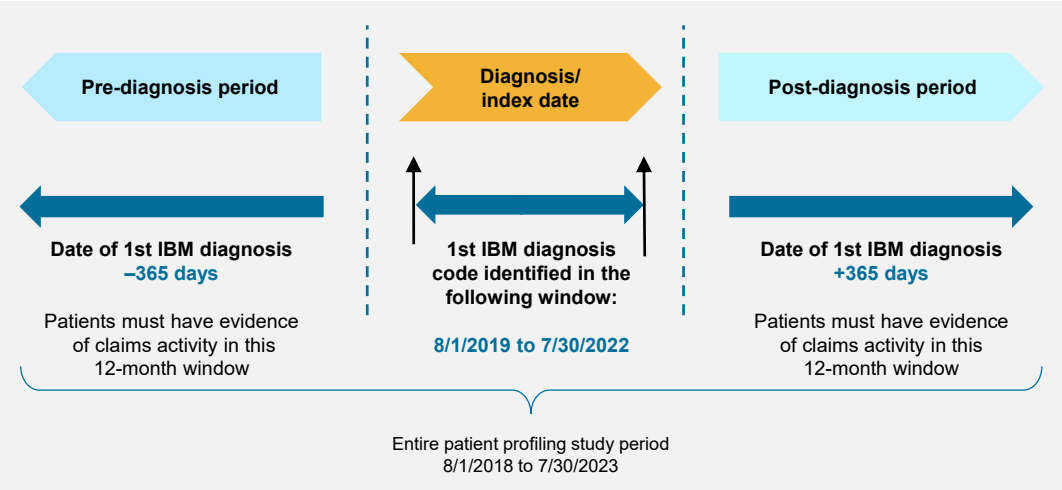
- Inclusion body myositis (IBM) is a rare, progressive muscle disease characterized by the invasion of healthy muscle by highly differentiated, cytotoxic CD8+ T cells that express the cell-surface receptor KLRG1¹⁻³
- IBM typically presents in individuals with a mean age >60 years and is associated with profound functional impairment due to loss of grip strength, difficulty walking, and/or dysphagia^{1,4,5}
- Estimates of the prevalence of IBM in the United States (US) range from 10.7 to 70.6 per million⁶⁻⁸
- The objectives of the current study were to describe the patient journey in IBM and estimate the number of symptomatic but undiagnosed patients with IBM in the US

Methods

Claims analyses

- The Real Chemistry US claims database was used to identify patients with ≥2 IBM diagnosis claims based on the Internal Classification of Diseases, Tenth Revision (ICD-10) classification system (ICD-10 code G72.41) and a matched control cohort without IBM; for patients with IBM, the first IBM diagnosis claim had to occur between 8/1/2019 and 7/30/2022 (**Figure 1**)

Figure 1. IBM patient cohort of interest



- Assessments included patient characteristics prior to diagnosis, time from first symptom to first diagnosis, any observed IBM-related symptoms, and healthcare resource utilization

Machine-learning analyses

- For machine-learning analyses, the Real Chemistry US claims database was used to synthesize an “Ideal Patient Population” (IPP) comprising patients with ≥2 IBM ICD-10 diagnosis claims between 1/1/2020 and 4/15/2024 (≥30 days apart) and a history of ≥1 muscle biopsy and/or myositis-specific antibody testing; this was compared with an age- and gender-matched random control cohort
- The diagnosis, treatment, and procedure codes of these patients were used to create a model that determined the probability of an undiagnosed but symptomatic patient having IBM
- Model performance was evaluated using receiver operating characteristic (ROC) and mean decrease in accuracy of significant features
- The model was tested in a separate cohort of clinically similar patients with IBM to confirm its predictive value and subsequently applied to all patients in the claims universe

Results

Claims analyses

Demographic characteristics

- Data from a total of 2435 patients were included in the analysis; 61% were male, and most presented with IBM later in life
- Patient demographic characteristics are presented in **Table 1**

Table 1. Demographic characteristics of patients with IBM

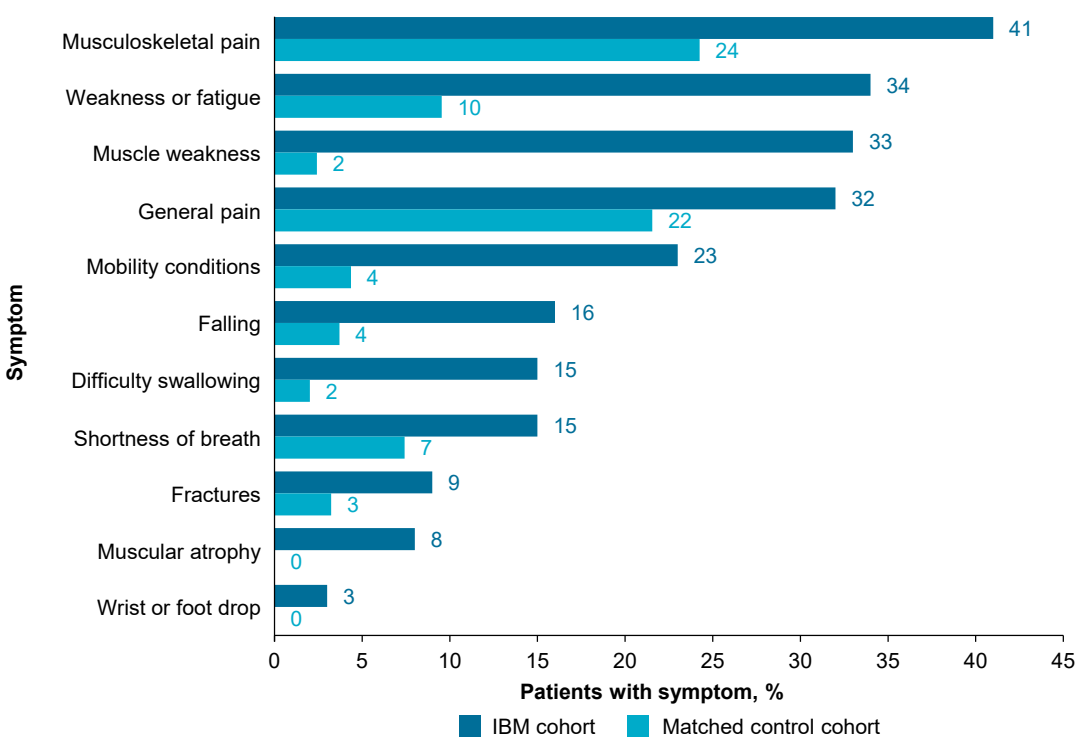
	Patients with IBM (n=2435)
Age at the time of first diagnosis, %	
0–24 years	1
25–34 years	1
35–44 years	2
45–54 years	7
55–64 years	19
≥65 years	71
Race and ethnicity, %	
White: Non-Hispanic or Latino	72
White: Hispanic or Latino	6
Black or African American	4
Asian	2
Unknown	16

IBM, inclusion body myositis.

Symptoms and time to diagnosis in patients with IBM

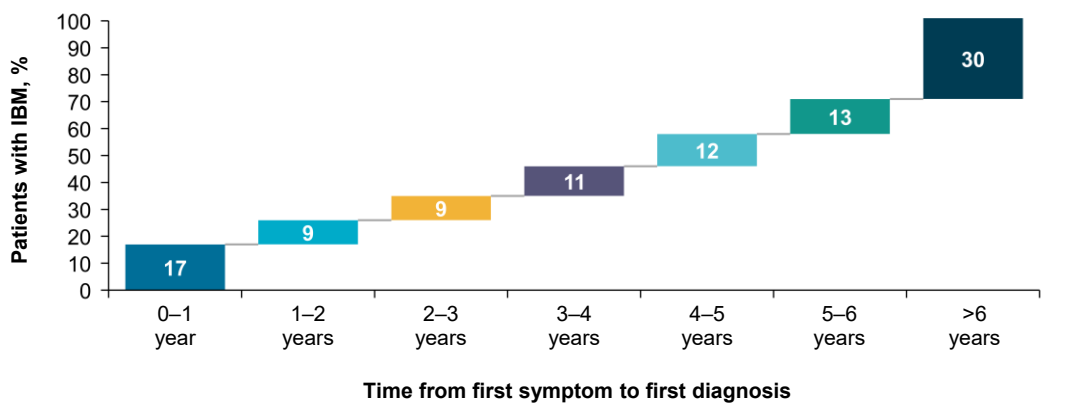
- Pain and weakness were the most common symptoms experienced by patients with IBM prior to diagnosis and were more commonly reported in patients with IBM compared with a matched control cohort (**Figure 2**)

Figure 2. IBM-related symptoms in patients with IBM (n=2435) prior to diagnosis



- Median time between first IBM-related symptom and first IBM diagnosis claim was 4.4 years overall (n=2384) and 3.3 years when musculoskeletal pain was excluded as a presenting symptom (n=2334)
 - Approximately 30% of patients with IBM had a time course of >6 years between their first symptom and their first diagnosis (**Figure 3**)

Figure 3. Time from first symptom to first diagnosis in patients with IBM (n=2384*)



*Patients with observed IBM-related symptom prior to diagnosis (ie, patients who had ≥1 IBM-related symptom diagnosis claim and ≥1 IBM diagnosis claim in their entire claims history). IBM, inclusion body myositis.

Healthcare resource utilization in patients with IBM prior to diagnosis

- In the year prior to diagnosis, patients with IBM were seen by a range of specialists (**Figure 4A**); 30% of patients presented to the emergency room (**Figure 4B**), with the 20% of those admitted staying for an average of 1 week (**Table 2**)

Figure 4. Specialists visited (A) and healthcare settings visited (B) by patients with IBM (n=2435) in the year prior to diagnosis

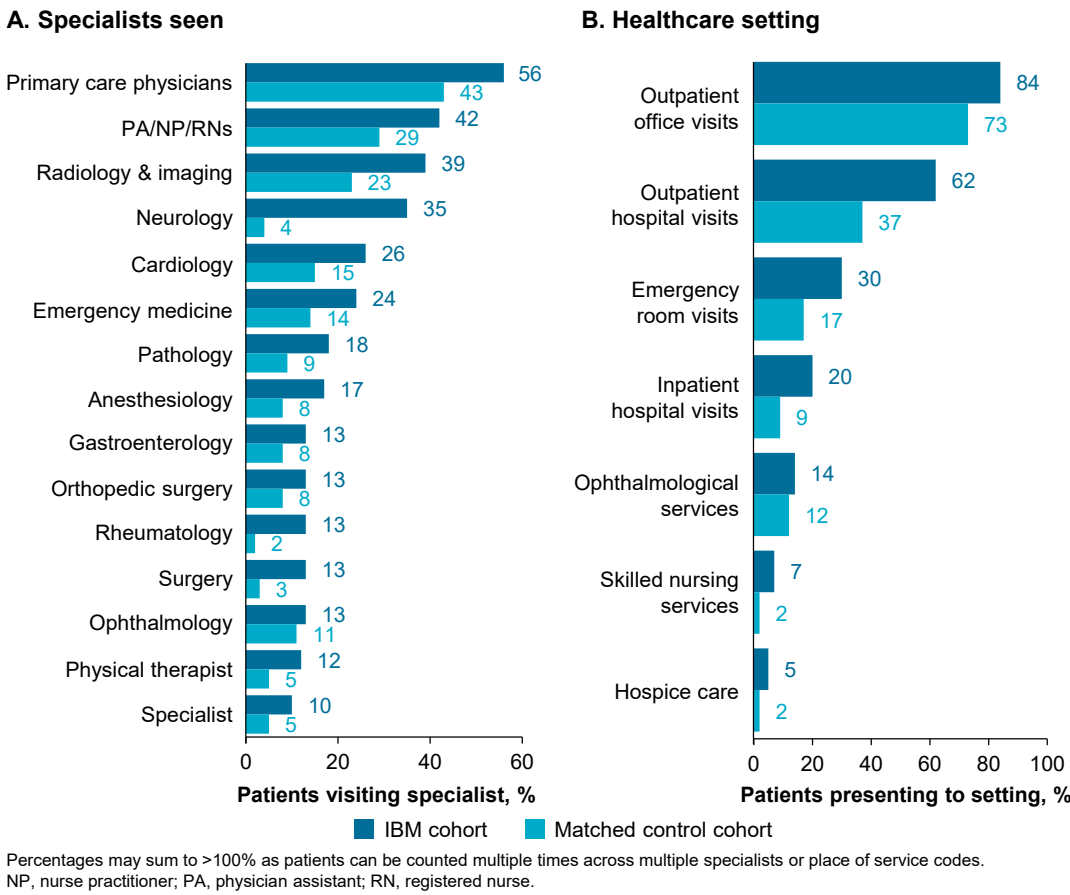


Table 2. Distribution of healthcare visits in patients with IBM (n=2435)

	ER visits	Inpatient visits	Inpatient visits length of stay	Outpatient hospital visits	Outpatient office visits
Patients, n (%)	735 (30)	498 (20)	498 (20)	1501 (62)	2053 (84)
Mean (median)	2 (1)	8 (3)	7 (3)	5 (3)	10 (6)
[Q1, Q3]	[1, 2]	[1, 7]	[1, 7]	[1, 6]	[3, 13]
per patient			days per visit		

Patient numbers reflect patients with a relevant CPT code or POS claim within each healthcare setting in the prediagnosis period. CPT, Current Procedural Terminology; ER, emergency room; POS, Place of Service; Q1, quartile 1; Q3, quartile 3.

Machine-learning analyses

Model setup

- Data from a total of 1633 patients newly diagnosed with IBM (between Jan 2020 and April 2024) who received muscle biopsies or myositis-specific antibody testing in all history were selected for the IPP and used for the training of a predictive model; 56% of these patients were male, and 74% were over the age of 65 years

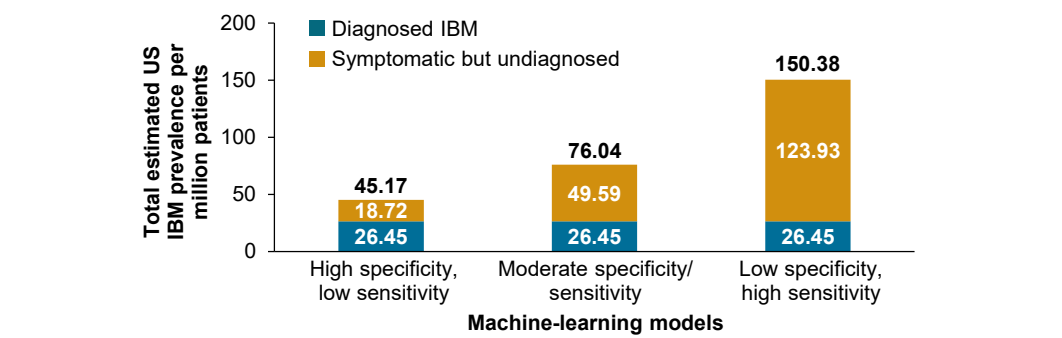
Model results

- ROC analyses demonstrated that the model was highly predictive, with area under the curve values ranging from 85% to 94% depending on the strictness of the criteria used; the model remained highly predictive when tested against a cohort of clinically similar patients
- Myopathy, muscular weakness, and procedural codes related to the diagnostic journey for IBM (eg, nerve conduction studies, surgical pathology) were identified as the top predictive variables driving the model
- In the subset of patients predicted by the model to have IBM, over 80% reported reduced mobility and 65% had a history of a fall

Prevalence data

- Using ICD-10 codes only, the estimated prevalence of patients diagnosed with IBM in the US was 26.45 patients per million using 2023 US census data (**Figure 5**)
 - Note that patients diagnosed with IBM not actively seeking treatment for IBM are not included in this analysis
- Depending on the specificity of the predicted patient cutoff ranges, the estimated projected prevalence of symptomatic but undiagnosed patients in the US ranged from 18.72 (high specificity) to 123.93 patients per million (high sensitivity) (**Figure 5**)

Figure 5. Estimated projected IBM prevalence per million patients in the US*



Prevalence of patients diagnosed with IBM was estimated using ICD-10 diagnosis codes; prevalence of symptomatic but undiagnosed patients with IBM was estimated using machine-learning models. Prevalence estimates were projected by a factor of 1/65% to account for national claims capture approximations. *Normalized to US census as of 2023 (total US population 334,000,000). IBM, inclusion body myositis; ICD-10, Internal Classification of Diseases, Tenth Revision; US, United States.

Conclusions

- Claims analyses indicated higher levels of pain and weakness and a higher level of healthcare resource utilization in patients with IBM relative to a matched control cohort
- Machine-learning analyses of claims data suggested there were at least as many symptomatic undiagnosed patients with IBM in the US as there were diagnosed patients with IBM
- Earlier recognition of patients with IBM is urgently needed if patients are to receive timely and appropriate care

Disclosures

DG: Employee of Real Chemistry; DB: Former employee of Real Chemistry; RM: Consultant to Abcuro; KT: Employee of Abcuro.

Acknowledgments

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