Epidemiology and patient journey in inclusion body myositis:

A machine learning methodology applied to claims data in the United States

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PLAIN LANGUAGE SUMMARY

Background and objectives

- Patients with a muscle disorder called **inclusion body myositis ("IBM")** are generally adults >60 years old who have increasing difficulty with everyday activities due to difficulties gripping objects, walking, and/or swallowing[1-3]
- In this study, researchers had 2 goals:
  1. To describe the experience of patients living with IBM, from initial symptom recognition to diagnosis and beyond
  2. To estimate the number of people in the United States who have symptoms of IBM but have not been diagnosed

How was the study done?

- For both analyses, researchers used a large database of health insurance claims, which included information about medical diagnoses and tests, to identify groups of patients with IBM in the United States
- For the first analysis, the investigators evaluated the specific symptoms a patient experienced, the types of medical appointments they had, and the time it took to receive a diagnosis of IBM
- For the second analysis, researchers used a type of artificial intelligence called machine learning to estimate the number of people in the United States who had symptoms of IBM but had not yet been diagnosed

What were the results?

- For the first analysis, health insurance claims from **2435 patients with IBM** were reviewed

Male

At least 65 years old at time of diagnosis

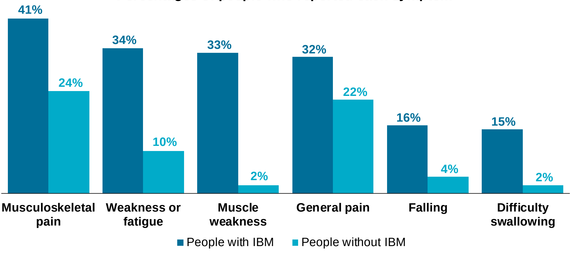
Visited the ER in the year before diagnosis

Median years from first symptom to a diagnosis of IBM

Median refers to the middle value in a set of ordered numbers.

- Pain and weakness were the most common symptoms experienced by people with IBM before their diagnosis, and these were more frequently reported in people with IBM than in people without IBM

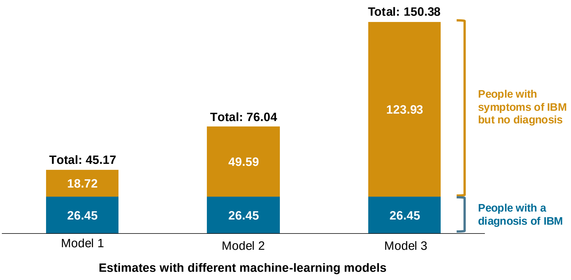
Percentages of people who reported each symptom



Musculoskeletal pain refers to pain that affects the bones, ligaments, muscles, tendons, or nerves.

- For the second analysis, health insurance claims from **1633 patients with IBM** were used to develop the machine learning models
- According to the researchers' calculations, there were approximately **26 people diagnosed with IBM** for every million people living in the United States; the researchers also found that there were somewhere between **19 and 124 people** per every million who had **symptoms of IBM but no diagnosis**

Estimated number of people with IBM per million people in the United States



Estimates with different machine-learning models

Researchers created 3 different models with different levels of confidence around whether people actually had IBM, with model 1 having the highest level of confidence and model 3 having the lowest level of confidence.

What did the researchers conclude?

- Patients with IBM commonly experienced muscle pain and weakness and waited more than 4 years for a diagnosis
- There were at least as many undiagnosed people with symptoms of IBM as there were people diagnosed with IBM in the United States
- Patient care may potentially be improved if healthcare providers could recognize patients with IBM sooner after their symptoms begin

References

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