Using cognitive interviews to develop a conceptual claims-based algorithm to identify patients with neuromyelitis optica spectrum disorder

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Introduction

Neuromyelitis optica spectrum disorders (NMOSD) are inflammatory disorders of the central nervous system characterized by acute attacks on the optic nerves, spinal cord, brain, and brainstem.

- These unpredictable attacks often lead to permanent neurologic deficits and disability, including blindness and paralysis.
- The economic and humanistic burden of these disorders is significant.

Being able to identify patients with NMOSD using International Classifications of Diseases (ICD) codes and distinguish them from patients with multiple sclerosis (MS), myelin oligodendrocyte glycoprotein antibody disease (MOGAD), and other central nervous system inflammatory disorders, would enable a more precise estimation of the burden of NMOSD. In this study, we conducted cognitive interviews with NMOSD experts in order to develop a claims-based algorithm.

Objectives/Aims

Develop an algorithm to identify patients with NMOSD in healthcare claims datasets.

Methods

We recruited 3 neurologists from across the United States (Massachusetts, Oregon, Texas). We conducted 2 cognitive interviews with each expert to develop candidate algorithms capable of accurately identifying patients with NMOSD using healthcare claims data alone.

1. During the first-round interviews, experts were asked about which diagnoses, medications, and procedures available in claims would both identify patients with NMOSD and distinguish them from patients with related neurological conditions.
2. In the second-round interviews, experts reviewed potential criteria that could be included in the final candidate algorithms.

Using the results of these interviews, we developed a primary algorithm and several alternative versions.

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Results

The primary algorithm developed is as follows:

- ≥18 years old

AND

- ≥1 NMOSD diagnosis **OR** (≥1 transverse myelitis **AND** optic neuritis diagnosis) **AND** ≥1 NMOSD drug*

OR

- ≥2 NMOSD diagnoses ≥90 days apart

AND NOT any of the following exclusion criteria:

- MS diagnosis or MS-specific disease modifying therapy* after the last NMOSD diagnosis or NMOSD drug*
- Sarcoidosis diagnosis after the last NMOSD diagnosis
- ≥1 immune checkpoint inhibitor*

*Refer to Table 1 for a list of drugs.

Iterations of this algorithm included sequentially adding or removing various elements (e.g., ≥2 NMOSD diagnoses ≥90 days apart, ≥1 NMOSD drug, sarcoidosis, or MS diagnoses).

Table 1. Drugs included in algorithm

Disease	Drugs included in algorithm
NMOSD	Azathioprine (AZA), Bortezomib (BTZ), Eculizumab (ECU), Inebilizumab, Mycophenolate mofetil (MMF), Rituximab (RTX), Satralizumab, Tocilizumab (TCZ)
MS	Alemtuzumab, Beta-interferon, Cladribine, Daclizumab, Dimethyl fumarate, Fingolimod, Glatiramer acetate, Mitoxantrone, Natalizumab, Ocrelizumab, Ofatumumab, Ozanimod, Siponimod, Teriflunomide.
Immune checkpoint inhibitors	Atezolizumab, Avelumab, Cemiplimab, Durvalumab, Ipilimumab, Nivolumab, Pembrolizumab

Conclusions

We have developed a primary algorithm and alternative versions that can be used to improve identification of patients with NMSOD in healthcare claims. The algorithms have inherently high face validity because the items included are based on clinical expertise and practice. Algorithm testing and validation using both medical chart review and billing data is ongoing and expected to substantiate our algorithms.