Validation of Claims-based Diagnoses of Adult and Pediatric Neuromyelitis Optica Spectrum Disorder and Variations in Diagnostic Evaluation and Treatment Initiation

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Neuromyelitis optica spectrum disorder (NMOSD) is a rare demyelinating disease in need of more studies to determine effective treatment regimens. The rarity of the disorder, however, makes large randomized-controlled trials challenging. Validation of the International Classification of Diseases, 9th Revision, Clinical Modification (ICD-9-CM) code for NMO could facilitate the use of large healthcare claims data for future research. We aimed 1) to determine the positive predictive value (PPV) of the ICD-9-CM code for NMO as well as evaluate case-finding algorithms for the identification of patients with NMO/NMOSD and 2) to compare the evaluation of and treatment for pediatric versus adult patients. This was a multicenter retrospective cohort study of patients with ? 1 ICD-9 code for NMO seen at 3 pediatric and 2 adult United States medical centers from 2001-2016. Using a standardized data entry form, pediatric and adult neurologists and rheumatologists reviewed patients' medical records to determine whether patients fulfilled the 2006 criteria for NMO and/or the 2015 criteria for NMOSD in order to determine the positive predictive value (PPV) for the ICD-9-CM code. Demographic and clinical information was abstracted from patient medical records to ascertain variables then evaluated in case-based finding algorithms for further identification of patients with true NMO/NMOSD. We also evaluated differences in clinical characteristics between pediatric and adult patients using chi-squared or Fisher's exact tests, as appropriate, to assess for treatment variation. A single code for NMO had a PPV of 47% across all sites, with significant site variation (0-77%). The best case-finding algorithm included at least 5 codes as well as a documented hospitalization (PPV = =90% for children and PPV = 92% for adults). Children were more likely to be evaluated by a rheumatologist or ophthalmologist, undergo magnetic resonance imaging of the orbits, and receive immunosuppressive and biologic agents than their adult counterparts. Rituximab was administered similarly among the two groups. The ICD-9 code for neuromyelitis optica (NMO) is inaccurate for identification of NMO/NMOSD. Using case-finding algorithms increases the PPV. The initial diagnostic evaluation and treatment of NMOSD differs significantly between children and adults.

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