ASSESSING FUNCTIONAL STATUS IN PEDIATRIC MULTIPLE SCLEROSIS PATIENTS

P. Niewczyk, A. Monroe, S. Dowdy, Y. Harris, C. Granger, J. Ness

Background: Approximately 3% to 5% of patients with multiple sclerosis (MS) experience symptom onset before age 18. Currently, there is no standard disability assessment tool specific to pediatric MS. This study compared two instruments, the WeeFIM and Kurtzke Expanded Disability Status Scale (EDSS), to measure disability in pediatric patients with MS. The WeeFIM instrument is a pediatric functional assessment measure for children with a variety of physical, cognitive, and developmental impairments. The EDSS is used to quantify disability in adult patients with MS but has not been validated in a pediatric MS population.

Objective: This study will assess the psychometric properties of the WeeFIM instrument compared with the EDSS (used as the “gold standard”) in pediatric patients with MS; additionally, the MS-related disability in a pediatric population will be described.

Methods: The study design is a retrospective cohort study. A sample of at least 50 pediatric patients with MS evaluated at The University of Alabama at Birmingham’s Center for Pediatric Onset Demyelinating Disease with complete assessments at two periods in time will be included. The reliability of each instrument will be assessed. The discriminate properties of each instrument will be assessed using logistic regression. Construct validity will be tested by confirmatory factor analysis, and Rasch analysis will be performed to determine unilinearity and the hierarchical properties of each instrument. Additionally, a receiver operator curve analysis will be performed on the WeeFIM to assess the sensitivity and specificity of the instrument. Finally, predictive validity will be assessed using multivariate modeling on instruments to determine which is more predictive of functional change over time.

Conclusion: This study will provide valuable information on the reliability and validity of two assessment instruments in a pediatric MS population and will help identify useful outcome measures for interventions in this youngest group of patients with MS.