Background: Pediatric multiple sclerosis (MS) patients require expensive disease-modifying treatments in order to maintain their quality of life as well as to limit long-term disability. Little is known about how pediatric MS patients maintain their insurance coverage once they age out of private or publicly funded health plans. Objectives: To assess health insurance coverage and self-reported health status of pediatric MS, transverse myelitis (TM), optic neuritis (ON), and neuromyelitis optica (NMO) patients. The survey is meant to capture information regarding the transition years of patients from process to effectiveness. Methods: We interviewed demyelinating patients who had aged out of the UAB Center for Pediatric Onset Demyelinating Disease (CPODD) clinic and were aged 19 years or older at the time of the survey. Three telephone interview attempts were made, and then questionnaires were mailed to the last known address. From the CPODD practice, 24 patients met the requirements of our survey, and 11 patients responded (8 with MS, 1 with ON, 1 with NMO, and 1 with TM; 7 female and 4 male patients). Results: Upon leaving the pediatric clinic, 73% of the patients transitioned to an adult MS specialist. At the time they stopped coming to CPODD, 90% of the patients had some form of insurance. At the time of the survey, 90% of the patients still had health insurance coverage. Of the 10 insured patients, 10% were insured through employer-based health insurance, 30% were insured through Medicaid, and 60% were insured through a parent’s employer-based health insurance. We found that 73% of the patients had applied for disability benefits (SSI); 55% indicated that they had been approved and were currently on disability. Of the 6 patients who reported being on disability, 3 had MS, 1 ON, 1 NMO, and 1 TM. However, nearly half of the patients indicated that they were receiving government assistance in the form of food stamps and housing subsidies. Conclusions: We found that our pediatric MS and demyelinating patients successfully transition to adult care with proper clinical guidance. A large proportion of them maintain health insurance, either through publicly funded programs or a parent. Only a small percentage reported trouble paying for medications.

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