Future Perspectives

The educational impact of childhood-onset multiple sclerosis: Why assessing academic achievement is imperative

WS Vargas, KG Noble, B Banwell and P De Jager

Abstract

Background: Limited data suggest that adolescents with multiple sclerosis (MS) frequently discontinue school. While it is known that cognitive impairment occurs in 30% to 50% of children with MS, the functional impact of childhood MS on academic achievement is virtually unknown.

Objective: To that end, this paper builds an evidence-based argument for evaluating educational outcomes in children with MS.

Methods: This will be accomplished through (a) a review of pediatric MS and its cognitive consequences; (b) a selective review of the utility of neuropsychological batteries in assessing academic outcomes in pediatric populations in general; and (c) a brief overview of modifiable factors that have a potential benefit on school outcomes in children with MS.

Conclusion: Scholastic achievement should be assessed as part of the routine cognitive screening of children and adolescents with MS.

Keywords: Multiple sclerosis, academic success, achievement, schools, adolescent, child cognitive dysfunction

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Introduction

Pediatric multiple sclerosis (MS), defined as onset of the disease before age 18, constitutes 2% to 10% of all cases of MS.1 Recent studies of children and adolescents with MS have consistently found cognitive impairment in one-third of patients.2 The daily impact of cognitive disability for adults with MS has been extensively examined and includes difficulty in shopping independently, driving, using public transportation, and loss of employment.2,3 Yet in children with MS, where cognition is vitally important to the formative process of education, research is lacking on the impact of cognitive impairment on daily childhood activities, namely, scholastic performance. The extent to which cognitive impairment in children with MS affects their educational outcomes is unclear. It is imperative that educational outcomes among children with MS become a priority in future basic, observational, and translational research.

Cognition in pediatric MS

Cognitive impairment is a prominent symptom of pediatric-onset MS. The frequency of cognitive impairment in pediatric MS studies ranges from 30% to 50%.2,4–9 Risk factors for cognitive dysfunction include early age at onset of MS,2,7 increased T2-weighted brain lesion load,10 reduction in global and regional brain volume,10 and overall neurological disability.2 The functional impact of MS on educational outcomes among these youngest patients is currently not well-characterized. In one international study of 23 adolescents with MS from Italy, Canada, and the United States, 39% had discontinued high school over a five-year period.11 In a separate study, 9% of children with MS dropped out of school over a 2.5-year period.12 Comparing these numbers among teens with MS to the overall US national drop-out rate of 6%, the difference is striking. Examining academic performance in children with MS would allow for the development of screening batteries for identification...
of children at risk of poor school outcomes. This, in turn, could lead to implementation of educational rehabilitation programs, which have been shown to be effective for children with neurologic injury and cognitive deficits.

Assessing academic outcomes in pediatric populations

While many pediatric studies have examined cognition using traditional neuropsychological batteries,2,10 a few studies have formally assessed academic achievement, which may provide a better indication of future success. We define academic achievement as the extent to which a student has attained his or her educational goals. There is no general consensus on how best to evaluate academic achievement or which variables have the greatest impact.13 It is almost always referenced in an aggregate form as grade point average (GPA) or grades in a course.14 While academic achievement should be the direct result of attaining learning objectives and acquiring desired competencies, this is not always the case as grades and GPA capture a student’s ability to meet performance criteria and not necessarily their learning. Thus, the definition of academic achievement remains amorphous, lacking clarity, and operationalization.14

Despite academic achievement being one of the most researched outcomes in education, there is no complete presentation of empiric instruments available to measure academic success.14 In the literature, 55% of all studies investigating academic achievement measure GPA as the primary outcome14 (Table 1). However, differences in grading approaches and diversity in curricula make GPA an unreliable marker of educational achievement in a research context. An additional challenge in this area includes the diversity of student abilities. Neuropsychological assessment is often obtained in children with neurological diseases who either have or are pursuing individualized educational plans (IEPs). An IEP is a legally binding document describing a child’s special education services and is developed after a child has undergone evaluation for determination of special services. Although IEP implementation has theoretical benefits, paradoxically, greater specification of progress monitoring on the IEPs of low-achieving students was associated with lower performance on state-wide achievement tests.15 Thus, based on limited data, IEPs in the context of academic achievement research are unlikely to significantly impact standardized test scores, although there may be some expected effects on grades and GPA. A focus on standardized tests such state-wide tests of scholastic achievement and the Woodcock-Johnson Tests of Achievement (WJIII),16 as opposed to individual grades and GPA, helps to eliminate some of the inherent biases of studying academic achievement.

Most of the current knowledge regarding the ecological validity of neuropsychological measures is the result of studies examining adult and older adult populations.17,18 Ecological validity refers to how well results obtained through neuropsychological assessment relate to and predict functioning in the natural environment, that is, how well neuropsychological testing predicts school and behavioral functioning. A few pediatric studies have actually examined this relationship. McCall19 found that the correlation of school-age measures of intelligence and indices of educational and occupational success is approximately \( r = 0.50 \pm 10.7 \). Ganesalingam et al.20 showed that neuropsychological measures of executive function in children who sustained traumatic brain injury were only weakly related to behavioral ratings of executive functions. Price et al.21 reported a modest relationship \( (R^2 = 0.54) \) of measures of attention and adaptive functioning in a clinical sample of 119 children. The currently available and widely utilized tests to assess cognitive impairment in children may not accurately and fully capture academic outcomes.

<table>
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<tr>
<th>Table 1. Types of outcomes measured as academic success in achievement literature.</th>
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<td><strong>Total</strong> ( n = 31 ) studies</td>
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<tr>
<td>Academic achievement</td>
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<td>Career success</td>
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<td>Acquisition of skills and competencies</td>
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<td>GPA: grade point average. Articles that used multiple measures were counted in each category. The percentages are calculated as the total number of articles that utilized the category of measure out of the total number of articles examined.</td>
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Moreover, studies across diverse pediatric neurological diseases have found a discrepancy between cognitive performance and academic achievement. Children with epilepsy have been shown to have poor academic progress despite normal intellectual ability. In a study of 78 children with epilepsy, Mitchell et al. showed that after adjusting for intelligence quotient (IQ), academic underachievement was frequent; 38% of children with epilepsy were underachieving in reading comprehension, 31% in mathematics, and 32% in spelling. General knowledge was particularly affected, with 50% of children with epilepsy demonstrating underachievement.

A similar discordance between cognition and academic performance has been noted in survivors of childhood stroke. Compared to norms, children with a history of stroke scored significantly lower on all academic measures ($p < 0.01$). 15% were impaired in spelling, 24% were impaired in word reading, and 54% were impaired in numerical operations. In this study, IQ and memory measures were obtained at two time points (mean follow-up 5.5 years), and the results revealed that none of the mean differences in IQ or memory testing changed over time. These results indicate that although up to half of children with stroke were impaired academically, they did not decline in a meaningful way on standard neuropsychological testing.

Given that the known ecological validity of pediatric neuropsychological testing is modest at best, and prior studies across child neurology in general demonstrate that tests of cognition are insufficient for detecting the full-scale impact of neurological disease on the developing brain, we advocate that functional outcomes—in particular academic performance—should be a standard part of the evaluation of a child with MS.

### Modifiable factors in pediatric MS

Fatigue and depression have been shown to be significant problems in children with MS. Moreover, mood and fatigue have been shown to influence cognitive functions in pediatric MS. However, no existing studies have examined interventions on fatigue and mood in pediatric MS as related to cognition. Only two published studies have directly investigated sleep in children with MS. In one study, children with MS described napping as occurring in the setting of daytime fatigue and this in turn disrupted sleep patterns and led to poor sleep quality. The relationship between physical activity and pediatric MS has been examined in several studies. Increased physical activity has been shown to correlate negatively with depression and fatigue in people with pediatric-onset MS. Given the interplay between sleep, mood, fatigue, and physical activity, these variables should be priorities in future studies of pediatric MS, as they are modifiable and allow for interventions that could improve cognition and academic outcomes.

### Conclusion and recommendations

The assessment of academic achievement is an important aspect of the comprehensive treatment of children with MS. The cognitive literature for varied pediatric neurological conditions shows that standard neuropsychological testing is inadequate for capturing academic deficiencies in these children. We recommend that children with MS undergo formal assessment of academic achievement using a standardized battery of tests measuring achievement in addition to any neuropsychological testing. Academic achievement can be assessed formally using standardized state-wide and national tests or by using the WJIII. WJIII is intended for use in educational, clinical, and research settings and has good construct validity and internal reliability. The WJIII has been used in a variety of student populations and is a validated tool for identifying students with academic and cognitive disabilities. For translational pediatric studies to actually focus on patient-centered outcomes, structured characterization of academic outcomes is necessary.

In our pediatric MS center, we have designed an ongoing study to distinguish cognitive performance from academic achievement. We intend to examine how the two are related in order to elucidate the daily impact of MS in childhood. By performing neuropsychological testing, administering tests of academic achievement, and collecting results of standardized state-wide exams, we will examine the concordance of academic performance with cognitive testing. Identifying whether cognitive performance affects academic performance in children with MS, and defining the clinical features associated with poor scholastic achievement in this group, is essential as these children have many years of formative education remaining. Such work will lead to areas of specific, targeted interventions to improve academic performance in youth with MS.

### Declaration of Conflicting Interests

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