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The Educational Impact of Childhood-Onset Multiple Sclerosis: Why Assessing Academic Achievement is Imperative

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Abstract

Background—Limited data suggest that adolescents with multiple sclerosis (MS) frequently discontinue school(1, 2). While it is known that cognitive impairment occurs in 30 to 50% of children with MS(3), 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; (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

Introduction

Pediatric multiple sclerosis (MS), defined as onset of the disease before age 18, constitutes 2% to 10% of all cases of MS(4). Recent studies of children and adolescents with MS have consistently found cognitive impairment in one third of patients(3). 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(5–8). Yet in children with MS, where cognition is vitally important to the

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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%(3, 9–11). Risk factors for cognitive dysfunction include early age at onset of MS(9), increased T2-weighted brain lesion load(12), reduction in global and regional brain volume(12), and overall neurological disability(3). 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 (U.S.), 39% had discontinued high school over a five-year period (1). In a separate study, 9% of children with MS dropped out of school over a 2.5 year period (2). Comparing these numbers among teens with MS to the overall U.S. national dropout 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(3, 12), few 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). Across the literature, 55% of all studies investigating academic achievement measure GPA as the primary outcome(14) (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. Though IEP implementation has theoretical benefits, paradoxically, greater specification of progress monitoring on the IEPs of low-achieving students was associated with lower performance on statewide achievement tests(15). Thus, based on limited data, IEPs in the context of academic achievement research are unlikely to significantly impact standardized test scores, though there may be some expected effect on grades and GPA. A focus on standardized tests such statewide 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. Few pediatric studies have actually examined this relationship. McCall found that the correlation of school-age measures of intelligence and indices of educational and occupational success is approximately r = .50 ± 10.7(19). Ganesalingam et al. showed that neuropsychological measures of executive function in children who sustained traumatic brain injury were only weakly related to behavioral ratings of executive functions(20). Price et al. reported a modest relationship (R2 = .54) of measures of attention and adaptive functioning in a clinical sample of 119 children(21). The currently available and widely utilized tests to assess cognitive impairment in children may not accurately and fully capture academic outcomes.

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 IQ, academic underachievement was frequent(22); 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 ($p < .01$). 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 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(23). Moreover, mood and fatigue have been shown to influence cognitive functions in pediatric MS(24, 25). 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(26, 27). 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(27). The relationship between physical activity and pediatric MS has been examined in several studies(28–30). Increased physical activity has been shown to correlate negatively with depression and fatigue in people with pediatric-onset MS(28). 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 Woodcock Johnson Tests of Achievement (WJIII)(16). WJIII is intended for use in educational, clinical and research settings and has good construct validity and internal reliability(16). The WJIII has been used in a variety of student populations and is a validated tool for identifying students with academic and cognitive disabilities(31, 32). 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 statewide 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.

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References

1. Grover SA, Sye A, Aubert-Broche B, et al. Young adults with pediatric-onset MS have a downward educational trajectory. Mult Scler J 2014; 20: 394.
2. MacAllister WS, Belman AL, Milazzo M, Weisbrot DM, Christodoulou C, Scherl WF, et al. Cognitive functioning in children and adolescents with multiple sclerosis. Neurology. 2005;64(8):1422–5. [PubMed: 15851734]
3. Julian L, Serafin D, Charvet L, Ackerson J, Benedict R, Braaten E, et al. Cognitive impairment occurs in children and adolescents with multiple sclerosis: results from a United States network. Journal of child neurology. 2013;28(1):102–7. [PubMed: 23155206]
4. Sikes EM, Motl RW, Ness JM. Pediatric multiple sclerosis: current perspectives on health behaviors. Pediatric Health Med Ther. 2018;9:17–25. [PubMed: 29595826]
5. Julian LJ, Vella L, Vollmer T, Hadjimichael O, Mohr DC. Employment in multiple sclerosis. Exiting and re-entering the work force. Journal of neurology. 2008;255(9):1354–60. [PubMed: 18677639]
6. Smith MM, Arnett PA. Factors related to employment status changes in individuals with multiple sclerosis. Multiple sclerosis. 2005;11(5):602–9. [PubMed: 16193900]
7. Staples D, Lincoln NB. Intellectual impairment in multiple sclerosis and its relation to functional abilities. Rheumatol Rehabil. 1979;18(3):153–60. [PubMed: 493802]
8. Marcotte TD, Rosenthal TJ, Roberts E, Lampinen S, Scott JC, Allen RW, et al. The contribution of cognition and spasticity to driving performance in multiple sclerosis. Archives of physical medicine and rehabilitation. 2008;89(9):1753–8. [PubMed: 18760160]
9. Amato MP, Goretti B, Ghezzi A, Lori S, Zipoli V, Moiola L, et al. Cognitive and psychosocial features in childhood and juvenile MS: two-year follow-up. Neurology. 2010;75(13):1134–40. [PubMed: 20876467]
10. Amato MP, Goretti B, Ghezzi A, Hakiki B, Niccolai C, Lori S, et al. Neuropsychological features in childhood and juvenile multiple sclerosis: five-year follow-up. Neurology. 2014;83(16):1432–8. [PubMed: 25217060]
11. Till C, Racine N, Araujo D, Narayanan S, Collins DL, Aubert-Broche B, et al. Changes in cognitive performance over a 1-year period in children and adolescents with multiple sclerosis. Neuropsychology. 2013;27(2):210–9. [PubMed: 23527649]
12. Till C, Ghassemi R, Aubert-Broche B, Kerbrat A, Collins DL, Narayanan S, et al. MRI correlates of cognitive impairment in childhood-onset multiple sclerosis. Neuropsychology. 2011;25(3):319–32. [PubMed: 21534686]
13. Kuh G, Kinzie J, Buckley JA. What Matters to Student Success: A Review of the Literature Commissioned Report for the National Symposium on Postsecondary Student Success: Spearheading a Dialog on Student Success Washington, DC: National Postsecondary Education Cooperative 2006.
14. York T, Gibson C, Rankin S. Defining and Measuring Academic Success. Practical Assessment, Research and Evaluation. 2015;20(5):1–20.
15. La Salle T, Roach A, McGrath D. The Relationship of IEP Quality to Curricular Access and Academic Achievement for Students with Disabilities. International Journal of Special Education. 2013;28(1).
16. Woodcock RW, McGrew KS, Mather N. Woodcock Johnson III Normative Tests of Achievement. 2001.
17. Beatty WW, Blanco CR, Wilbanks SL, Paul RH, Hames KA. Demographic, clinical, and cognitive characteristics of multiple sclerosis patients who continue to work. Journal of Neurologic Rehabilitation. 1995;9(3):167–73.

18. Morrow SA, Drake A, Zivadinov R, Munschauer F, Weinstock-Guttman B, Benedict RH. Predicting loss of employment over three years in multiple sclerosis: clinically meaningful cognitive decline. Clin Neuropsychol. 2010;24(7):1131–45. [PubMed: 20830649]
19. McCall RB. Childhood IQ's as Predictors of Adult Educational and Occupational Status. Science. 1977;197(4302):482–3. [PubMed: 17783247]
20. Ganesalingam K, Yeates KO, Taylor HG, Walz NC, Stancin T, Wade S. Executive functions and social competence in young children 6 months following traumatic brain injury. Neuropsychology. 2011;25(4):466–76. [PubMed: 21463038]
21. Price KJ, Joschko M, Kerns K. The ecological validity of pediatric neuropsychological tests of attention. Clin Neuropsychol. 2003;17(2):170–81. [PubMed: 13680424]
22. Mitchell WG, Chavez JM, Lee H, Guzman BL. Academic underachievement in children with epilepsy. Journal of child neurology. 1991;6(1):65–72. [PubMed: 2002204]
23. Parrish JB, Weinstock-Guttman B, Smerbeck A, Benedict RH, Yeh EA. Fatigue and depression in children with demyelinating disorders. Journal of child neurology. 2013;28(6):713–8. [PubMed: 22805247]
24. Goretti B, Portaccio E, Ghezzi A, Lori S, Moiola L, Falautano M, et al. Fatigue and its relationships with cognitive functioning and depression in paediatric multiple sclerosis. Multiple sclerosis. 2012;18(3):329–34. [PubMed: 21844064]
25. MacAllister WS, Boyd JR, Holland NJ, Milazzo MC, Krupp LB, International Pediatric MSSG. The psychosocial consequences of pediatric multiple sclerosis. Neurology. 2007;68(16 Suppl 2):S66–9. [PubMed: 17438240]
26. Zafar AB, Ness J, Dowdy S, Avis K, Bashir K. Examining sleep, fatigue, and daytime sleepiness in pediatric multiple sclerosis patients. Multiple sclerosis. 2012;18(4):481–8. [PubMed: 21965417]
27. Carroll S, Chalder T, Hemingway C, Heyman I, Moss-Morris R. "It feels like wearing a giant sandbag." Adolescent and parent perceptions of fatigue in paediatric multiple sclerosis. Eur J Paediatr Neurol. 2016;20(6):938–45. [PubMed: 27422092]
28. Grover SA, Aubert-Broche B, Fetco D, Collins DL, Arnold DL, Finlayson M, et al. Lower physical activity is associated with higher disease burden in pediatric multiple sclerosis. Neurology. 2015;85(19):1663–9. [PubMed: 26268901]
29. Grover SA, Sawicki CP, Kinnett-Hopkins D, Finlayson M, Schneiderman JE, Banwell B, et al. Physical Activity and Its Correlates in Youth with Multiple Sclerosis. J Pediatr. 2016;179:197–203 e2. [PubMed: 27717498]
30. Kinnett-Hopkins D, Grover SA, Yeh EA, Motl RW. Physical activity in pediatric onset multiple sclerosis: Validating a questionnaire for clinical practice and research. Mult Scler Relat Disord. 2016;10:26–9. [PubMed: 27919494]
31. Schrank F Using the Woodcock-Johnson III with Individuals with ADHD. The ADHD Report. 2005;13(5):9–11.
32. Abu-Hamour B, Al Hmouz H, Mattar J, Muhaidat M. The use of Woodcock-Johnson tests for identifying students with special needs-a comprehensive literature review. Cyprus International Conference on Educational Research (Cy-Icer-2012). 2012;47:665–73.

Table 1

*:Types of Outcomes Measured as Academic Success in Achievement Literature

Total n = 31 studies		**n (%)**
Academic Achievement	GPA	17 (**55**)
	Grades	4 (**13**)
Career Success	Extrinsic	3 (**10**)
	Intrinsic	2 (**6.5**)
Satisfaction	Overall School Experience	3 (**10**)
	Course Experience	1 (**3**)
Persistence	Degree Completion Rate	1 (**3**)
	Retention	6 (**19**)
Acquisition of Skills and Competencies	Critical Thinking	6 (**19**)
	Academic Skills	5 (**16**)
	Affective Outcomes	4 (**13**)
Attainment of Learning Objectives	Engagement	5 (**16**)
	Institutional Objectives	4 (**13**)

Note: 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.

*Adapted from York, T et al(14)