

The psychosocial consequences of pediatric multiple sclerosis

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Abstract—Although psychological distress and cognitive dysfunction are well documented in adults with multiple sclerosis (MS), they are poorly understood in children with the disease. Psychosocial difficulty experienced by children and adolescents with MS involves factors common to all chronic illnesses in children, as well as MS-specific factors. The psychosocial manifestations of the disease may affect the patient's self-image, role functioning, mood, and cognition to adversely affect schooling, interpersonal relationships, and treatment compliance. Furthermore, the impact of having a family member with MS may affect overall family functioning. Assessment and interventions for psychosocial and cognitive problems in pediatric MS should be multidisciplinary in nature and address the child's functioning at home, school, and among peers, as well as the effect on the family.

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Multiple sclerosis (MS) is a chronic demyelinating disease of the CNS in which major depression, cognitive dysfunction, and psychological distress are common. While these problems are well documented in adults with MS, they are poorly understood in children with the disease. Although neurologists may not be directly involved in interventions for psychosocial issues as such care is often relegated to psychologists, social workers, and school personnel, sensitivity to such issues is important so that appropriate referrals for assessment and treatment can be made.

Both children and adults face challenges related to the unpredictable nature of the disorder, its direct and indirect behavioral changes, and the potential for major disability. Helping children with MS manage their psychosocial challenges is complicated by the paucity of research in this area, the unknown consequences of a demyelinating process during a period of ongoing myelinogenesis, and the varied needs of children, preadolescents, and older teens. Adolescents are the most common age group affected by pediatric MS. For this group, clinicians must be sensitive to the difficulties teens face coping with a neurologic disease and must recognize that teens may be particularly psychologically vulnerable. The present review is drawn from the extant research on pediatric MS, is informed by literature on the psychosocial factors in other chronic illnesses in children, and is illustrated by case examples drawn from our own clinical experience with this group.

Overview of behavioral problems. The prevalence of behavioral concerns in the pediatric MS population is largely unknown. The few studies available cite frequency rates from rare¹ to over 50% of children experiencing depression, anxiety, or adjustment disorders.² Factors contributing to psychosocial difficulty can be categorized by chronic illness disease features common to childhood disorders and by disease-specific factors unique to MS.

Adjusting to a chronic illness does not invariably lead to emotional dysfunction^{3,4}; however, it is likely that youths with MS, like youths with diabetes and epilepsy,⁴ may be at greater risk for behavioral problems. The sense of isolation, the dependence on long-term treatment, and the need for constant self-management reinforce the feeling of being different from peers. Children with chronic medical disease can test the endurance of clinicians and families with risk-taking behaviors (e.g., alcohol, smoking) and poor compliance with medical treatment.^{5,6}

MS-specific factors that can lead to behavioral problems include the physical disabilities and other challenges associated with neurologic impairments, the relative isolation associated with a disease that is rare in children, and the unpredictable nature of the disease course. Symptoms of MS that can be particularly problematic are severe fatigue, motor impairments, visual loss, and bladder dysfunction. The physical effects of MS, its rarity, and its unpredictable course may lead to negative effects on a

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child's self-perception as is so commonly seen with other chronic medical illnesses in childhood.⁷⁻⁹

Fatigue can limit a child's ability to attend school on a full-time basis. Gait impairments interfere with getting to class, particularly for middle school and high school aged students who travel between several classrooms daily. Bladder or sphincter dysfunction, though somewhat less common in children than adults with MS,¹⁰⁻¹² has been misinterpreted by teachers and other school staff. For example, a teen with MS frequently asked permission to go to the bathroom during class. Her teacher misinterpreted this behavior as a sign of poor class participation and insubordination rather than recognizing this as a manifestation of her disease. Until school personnel were educated, the student's grades were adversely affected by this misperception.

The unpredictable nature of MS adds to the sense of uncertainty and can threaten adherence to treatment; children with infrequent relapses may fail to recognize that their medications have likely influenced the disease course and prematurely cease taking them. Because MS in children and adolescents is relatively unusual, there are few support mechanisms available for affected children and families. Historically, most programs offered by local National MS Society chapters have been oriented toward adults, although a national support program has been in place since 1990. Fortunately, as awareness of MS in younger persons has grown, more Society resources are available.

Consequences. The multiple factors underlying psychosocial stressors can differentially affect children and adolescents and consequences are observed as follows:

- Effects on the individual
- Impact on school and other aspects of social functioning
- Stress on the family
- Poor communication with health care providers

Consequences for the individual. Individuals may exhibit abrupt changes in behavior that may raise overall health and safety concerns and necessitate further assessment and management.⁵ Risk-taking behaviors, when severe, can lead to running away from home, acting out through promiscuous sexual behavior, substance abuse, or criminal activity such as shoplifting or vandalism.⁶ Those who experience depression may express this through repetitive crying, social withdrawal, and possibly through self-injury or suicide attempts.

Consequences in school. Teachers may note behavioral changes that create challenges for parents, teachers, and peers. Reports of uncharacteristic disruptive behavior in the classroom, open opposition to teachers' demands and expectations, incomplete assignments, truancy, physical aggression toward peers, and any behaviors that lead to suspension or expulsion clearly indicate a cause for concern.⁶ In our experience missed days of school due to sick days,

hospital admissions, and medical appointments are frequent. Furthermore, school personnel may be unaware of the unpredictable waxing and waning of symptoms in MS. For example, a girl with optic neuritis may need significant support with note taking, written examinations, and to simply get around the school. As her symptoms resolve, she may no longer require such support.

Adolescents and parents may question future educational and career goals. Some examples from our experience have included a young man with MS who dreams of attending a military academy and has questions about how to disclose his diagnosis to the medical screening board. Another example is the family of a girl with MS that debates whether to disclose her diagnosis to the coach of the college crew team when applying for a scholarship.

Consequences on the family. Chronic illnesses affect the whole family. Factors that predict better coping with chronic illnesses include good communication, a supportive and expressive family atmosphere, and external support from friends and health care providers.^{8,13} Successful family adaptation often includes an acknowledgment of the disease, minimization of abnormalities related to the chronic illness, defining family life as essentially normal, defining the social consequence of the situation as minimal, and engaging in behaviors designed to demonstrate the essential normalcy of the family to others.¹⁴

Specific to pediatric MS, parents frequently report feeling lost. Families of our patients have reported that when speaking to their friends or relatives, they have heard statements such as "MS doesn't happen in kids." They rarely have the opportunity to meet other parents sharing the same experience and, in comparison to adult MS, there is little available literature. More generally, parents of children with chronic illness often mourn for the loss of the healthy child and the loss of the dreams they harbor for their child's future. Common concerns include issues surrounding the health of the child, future family planning, and concerns regarding access to medical care, medical insurance, and financial resources that the child will require.

Consequences on health care. While medication compliance is a challenge for most patients, it may be particularly difficult when facing a chronic illness for which treatment must become a permanent fact of life. Compliance rates of children with chronic illnesses often decrease as children reach adolescence.⁷ Some adolescents may refuse to adhere to the recommended treatment regimen, continually combat use of injectable treatments, or resist access to health care for acute and ongoing needs.¹⁵ One study found that injection anxiety is a determinant of adherence to therapy in adults with MS.¹⁶ In pediatric MS, compliance is even more difficult due to the abstract nature of treatment. In our experience, children and parents may struggle with accepting the need to continue therapy when they have not had a relapse and therefore seem healthy.

Cognitive function in pediatric MS. Cognitive problems in MS affecting memory, attention, and cognitive processing speed occur in 40 to 60% of adults.¹⁷ Cognitive dysfunction in children and adolescents with MS has been less well studied, but children may be especially vulnerable to cognitive impairment given that the neuropathologic processes of MS co-occur with the myelination in the developing CNS. There are too few studies of children with MS to accurately estimate how frequently they experience cognitive dysfunction. However, in a study of 37 children with MS who underwent cognitive assessment, a third of patients had impairments on two or more neuropsychological tests.²

Case studies in children with MS have demonstrated deficits in global measures of IQ, perceptual motor skills, memory, visual-motor deficits, executive functions, and processing speed.^{1,18-20} The deficits in cognition affect school performance. A comprehensive case study of an 11-year-old boy with MS onset at age 9 demonstrated clear visual-motor deficits and impaired executive functions that led to declining academic performance despite intact reading, writing, and mathematics ability.²¹ Likewise, in larger studies of children, a variety of consequences on school functioning have been noted, including special accommodations in school, such as reduced work load due to fatigue, or compensatory strategies to assist with memory deficits.^{2,20} Other cases from our experience have included the need to be transferred out of a gifted program into remedial classes and the need to go on medical leave from college.²

The disease correlates of cognitive impairment in childhood MS have only begun to be examined. Both high relapse rate and Expanded Disability Status Scale (EDSS) have been shown to be associated with cognitive deficits.² However, children with few other signs of neurologic dysfunction and low EDSS are also at risk for cognitive dysfunction. Two studies have noted that cognitive impairments appear relatively early in the disease course and that patients with longer disease duration will demonstrate greater impairment.^{2,20} The limited longitudinal data available suggest that some children will show progressive decline in cognitive performance over time.^{2,22}

Assessment. The relative contribution of physical factors, medication side effects, and changes in the disease course need to be considered in the assessment of psychosocial functioning. For example, initiation of interferon or steroid therapies may affect mood or lead to a sudden behavioral change.²³ A key component of a behavioral assessment is the joint interview with parents and the child to investigate problematic behavior. Structured behavioral rating scales (e.g., Child Behavior Checklist and Teacher Rating Scales) may be helpful.²⁴ An identified behavioral issue requires in-depth exploration to assess its relation to the individual's developmental stage, factors that may trigger the behavior, and the parents'

response to the behavior.²⁵ When assessing the behavior of a child with MS, it is important to avoid making the assumption that the behavior is directly related to having MS. For example, pre-existing family dysfunction or a drastic change in a child's life such as parental separation/divorce or death or a family move may be the main contributing factor to the behavioral presentation. A thorough assessment of the behavioral issue provides important information for developing the most appropriate management plan.

With respect to cognitive functioning, psychoeducational testing conducted by schools, which typically involves broad IQ measures and measures of academic achievement, is likely to be too insensitive to identify MS-specific cognitive deficits. Therefore, a more comprehensive evaluation by a neuropsychologist familiar with evaluating children is warranted when cognitive impairment is suspected or decline in school function has been observed.

Intervention. Behavioral problems may require a referral to a therapist, social worker, psychologist, or psychiatrist who specializes in counseling of children and adolescents with chronic illnesses. Recognizing risk factors and implementing preventative strategies to reduce the emergence of behavioral problems is an ideal practice. This includes affording opportunities to express emotions, feelings, and fears, optimally managing physical symptoms, limiting the severity of medication side effects, providing education, involving the child or adolescent in health care decision-making, and offering anticipatory guidance and counseling. The use of a proactive approach potentially limits the development of behavioral issues.

Open discussion of the family's concerns is critical. While some families may need family therapy or individual psychotherapy, it is not uncommon for there to be a great deal of resistance. In these cases, the clinicians involved in the MS care will need to be more involved with the family problems.

Interventions to address the frequent feelings of isolation have been developed. A program to bring adolescents with MS together in a camp setting was developed at the National Pediatric MS Center at Stony Brook and this model is being replicated elsewhere. Post-event interviews of campers have shown a feeling of cohesion and belonging among attendees and feedback via structured phone interviews from parents of the teens indicate that they found that their children are defined by more than their MS. Other programs offered through the NMSS provide support for parents of children with MS through conference calls and list serves. A program to match children up with pen pals has also been established.

If cognitive deficits are identified, a number of strategies may be employed at schools to minimize the effect on daily function. Examples include the following:

- Preferential seating to reduce distractions and to facilitate the teacher's ability to monitor a

child's attention when attention deficits are identified

- Reduced work load and extended time limits on tests (including standardized state evaluations) may be warranted if processing speed or motor speed deficits exist
- Assistance with visual tracking when reading can assist students with visual spatial deficits
- Occupational therapy to address visual spatial deficits and improve map reading and navigational skills
- Assistive technology to help students with deficits in manual dexterity (e.g., voice recognition software for those with writing difficulty)
- Interventions to improve memory

Memory deficits pose unique challenges in the classroom. Careful neuropsychological evaluation can identify specific areas of deficiency such that encoding and retrieval can be maximized. For example, memory deficits may be modality specific, that is, affecting verbal memory more than memory for visually presented information. Such information can be helpful in remediation planning. Research on cognitive rehabilitation in MS has been mixed, but it is generally held that interventions that are compensatory in nature, i.e., use cognitive strengths to work around areas of deficits, are more successful than interventions designed to restore lost function. Whether medications found to be effective in adults with cognitive impairments should be considered in children is not yet known.

Summary. The psychosocial manifestations of MS in children and adolescents may affect the patient's self-image, role functioning, mood, and cognitive function. Furthermore, the impact of having a family member with MS may have adverse affects on the overall family function. Assessment and interventions for such problems should ideally be multidisciplinary in nature and address the child's functioning at home, school, and among peers, as well as address the ramifications of the diagnosis for the family. Successful treatment may involve medication management, psychotherapy (for both the identified patient as well as family members), and academic interventions.

Appendix

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