Multiple sclerosis in childhood: Understanding and caring for children with an “adult” disease

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Abstract
Multiple sclerosis (MS) is rare in childhood but may occur more frequently than originally believed. In light of the complex nature of MS, the expanding availability of new MS treatments, and the developmental needs of pediatric patients, multidisciplinary care of pediatric patients with MS is a necessity. Our review of MS in childhood aims to increase the awareness of neuroscience nurses about MS in children and adolescents, and to expand the knowledge of pediatric nurses concerning this “adult” disease. Our experience in developing a multidisciplinary pediatric MS clinic that addresses both health and developmental needs of children with MS is presented and discussed. The nurse’s role in the care of these children and their families through assessment, support, education, advocacy, referral and coordination of care is emphasized.

Introduction
Contrary to the common belief that multiple sclerosis (MS) is an “adult” disease, children do develop MS. Although MS typically presents in young adults between the age of 20 and 40 years, children with onset as young as 10 months have been reported (Ghezzi, Deplano, Faroni, Grasso, Liguori, & Marrosu, 1997; Shaw & Alvord, 1987). MS is considered rare in childhood, however, retrospective reviews indicate that up to five per cent of patients with MS are diagnosed before their eighteenth birthday (Brett, 1995; Cole & Stuart, 1995; Ghezzi et al., 1997; Iannetti, Marciani, Spalice, Spanedda, Raucci, & Trasimeni, 1996; Sindern, Haas, Stark & Wurster, 1992). In addition, some adults with MS report experiencing symptoms in childhood or adolescence that may have been the initial manifestations of MS. This raises the possibility that the diagnosis of MS in children is delayed until recurrent symptoms present in adulthood. With the advent of therapies that have the potential for reducing the frequency and severity of exacerbations, and slowing progression of disability, prompt identification of pediatric patients is imperative. Furthermore, children and adolescents who are diagnosed with MS deserve coordinated care by health care professionals dedicated to meeting their complex needs.

An overview of pediatric MS, its diagnosis and treatments will be discussed, along with our experience in developing the first multidisciplinary pediatric MS clinic in North America. Nursing involvement with the care of these children and their families will be emphasized.

Pathophysiology
In multiple sclerosis, an autoimmune attack against the central nervous system (CNS) leads to demyelination, inflammation, and ultimately, the destruction of axons (Luchinetti, Brueck, Rodriguez & Lassmann, 1998; O’Connor, 1998). Demyelinated lesions, or plaques, are scattered throughout the CNS but are most frequent in the optic nerves, brainstem, spinal cord and periventricular white matter. It is hypothesized that activated T-cells, B-cells and macrophages gain access to the CNS via a break in the blood brain barrier (Morrison, 1999). The T-cells bind with myelin proteins and release inflammatory cytokines leading to selective destruction of myelin and oligodendrocytes. It is believed that B-cells produce antibodies against oligodendrocytes, and macrophages selectively strip the myelin. The patchy demyelination and axonal damage causes an interruption in nerve conduction and function leading to clinical signs and symptoms. The severity of symptoms is associated more with the location (eloquence of the affected area) rather than the size and extent of the lesion(s) (Paty & Ebers, 1998).

Incidence
The incidence of pediatric MS is not systematically documented and may be underestimated. A study of 418 patients with MS indicated that 17% had onset of MS by 21 years of age (Pinhaus-Hamiel, Barak, Siev-Ner & Achiron, 1998). Other extensive reviews of MS patients suggest that 2.7-5% develop symptoms before age 16 years (Duquette, Murray, Pleines, Ebers, Sadovnick, & Weldon, 1987; Ghezzi et al., 1997; Sindern et al., 1992). The incidence may be higher than reported due to a delay in diagnosis until adulthood. Improved diagnostic measures, the impetus to diagnose and implement treatment early, and increased awareness of pediatric MS may lead to more timely diagnosis and accurate reports of patients with onset of MS before 18 years of age.

Types of MS
As with adults, the majority of children begin with a relapsing-remitting (RRMS) course of the disease. In studies of children with MS, 53.5%-65.1% have the relapsing-remitting type of MS (Cole & Stuart, 1995;
RRMS is characterized by periods of acute neurological dysfunction called relapses, attacks, or exacerbations followed by periods of complete or partial recovery with no progression of the disease between relapses (Morrison, 1999; O’Connor, 1998). Symptoms must last longer than 24 hours, occur at least one month apart and produce clinical signs or paraclinical evidence to be considered an individual relapse (Paty & Ebers, 1998). Pseudo-relapses are transient events that occur in conjunction with physiological stressors such as fever, infection, environmental heat, electrolyte abnormalities and drugs, and present as a recurrence of prior symptoms or signs (Morrison, 1999). The annual relapse rate for children is reported to be 0.1 to four relapses per year (Pinhaus-Hamiel et al., 1998; Sindern et al., 1992).

Many children with RRMS go on to develop the secondary-progressive (SP) type of MS. In childhood, 22%-29.5% of MS patients will have SPMS (Cole & Stuart, 1995; Duquette et al., 1987; Ghezzi et al., 1997). After an initial phase of RRMS, the disease begins to cause progressive neurological impairment (O’Connor, 1998). There may continue to be occasional relapses with minor remissions and plateaus (Morrison, 1999). The length of time for children to progress from a relapsing-remitting course to a secondary progressive course is not documented in the studies reviewed. However, rate of relapse is found to correlate with rate of progression (Sindern et al., 1992). The influence of the child’s developing brain and immature immune system on the progression of MS is unknown. Although the retrospective study by Cole and Stuart suggests that early onset confers some degree of protection against rapid progression of MS, a prospective study examining the outcome of MS in children is required to confirm these findings.

The primary progressive (PPMS) form of MS is infrequent in childhood. PPMS reportedly occurs in 5.4%-22% of patients diagnosed before age 16 years (Cole & Stuart, 1995; Duquette et al., 1987; Ghezzi et al., 1997). However, it is difficult to determine the number of children who have PPMS in retrospective studies because investigators may not be able to accurately determine whether a child has been screened for leukodystrophy. From the onset of PPMS, disability slowly increases with no exacerbation or improvement of symptoms (Morrison, 1999; O’Connor, 1998). There is little variability in clinical course, however, a plateau may be reached (Paty & Ebers, 1998).

Diagnosis of MS

Currently, the diagnosis of MS is based on clinical features and paraclinical evidence of dysfunction in the CNS determined through clinical history, neurological examination, and magnetic resonance imaging (MRI). Evoked potentials (EPs) and cerebral spinal fluid (CSF) studies are also commonly performed (O’Connor, 1998; Paty, Noseworthy & Ebers, 1998). The diagnosis requires clinical evidence of two or more lesions in the brain and/or spinal cord that reflect white matter dysfunction disseminated in time and space. There must be at least two episodes of functionally significant symptoms lasting over 24 hours and separated by at least one month, and at least two physically discrete lesions located in the white matter. Slow, progressive development of symptoms evolving over six months also supports the diagnosis of MS (Paty, Noseworthy & Ebers, 1998).

In addition to a comprehensive clinical history and thorough neurological assessment, paraclinical tests and procedures assist with the detection of lesions and other CNS abnormalities. An MRI of the brain and/or spinal cord is performed to identify demyelinating lesions. White matter changes are common, even in normal individuals. For specificity, the MRI diagnostic criteria for MS includes evaluation of the size, shape, number and location of lesions (Paty, Noseworthy & Ebers, 1998). Lesions found on MRI may correlate with physical symptoms, but the MRI may also reveal “silent” lesions located in non-eloquent areas of the brain or spinal cord that do not produce noticeable symptoms (Miller, 1998; Paty, Noseworthy & Ebers, 1998). In adults, the number of MRI lesions typically exceeds the number of clinical relapses 10:1.

EPs are frequently performed to detect asymptomatic lesions. Although non-specific, prolonged latency in the EP can be used as evidence of white matter dysfunction in the optic nerves, brainstem auditory pathways, and spinal cord somatosensory pathways (Miller, 1998; Paty, Noseworthy & Ebers, 1998).

In addition, a lumbar puncture may be carried out to examine the CSF for IgG oligoclonal bands or for increased CNS synthesis of IgG (Poser, Paty, Scheinberg, MacDonald, Davis, & Ebers, 1983). Increased production of IgG in the CNS is considered one of the hallmarks of MS (Paty, Noseworthy & Ebers, 1998), but may also be found in patients with other inflammatory conditions of the CNS. The presence of oligoclonal bands in the CSF together with its absence in the serum is consistent with an immune response localized in the CNS and is indicative of abnormal IgG production in the CNS (Paty, Noseworthy &

Jennifer R. Boyd and Lynn J. MacMillan

16  VOLUME 22  ❖  NUMBER 2  ❖  DECEMBER 2000  AXON
Ebers, 1998). As with EPs, CSF studies are non-specific but in the presence of MS signs and symptoms provide laboratory support for the diagnosis of MS (Poser et al.).

**Presenting symptoms**

The presenting symptoms of MS are similar in both children and adults. However, children are more likely than adults to be systemically unwell (malaise, irritability, low-grade fever) at the time of disease onset (Bye, Kendall & Wilson, 1985; Cole & Stuart, 1995; Sindern et al., 1992); or exhibit symptoms suggesting diffuse encephalomyelitis, cerebral abscess or acute metabolic encephalopathy (Bye et al., 1985, Hanefeld, Bauer, Christen, Kruse, Bruhn & Frahm, 1991). Reported initial signs and symptoms in pediatric MS include motor deficits (weakness, impaired ambulation), sensory symptoms (numbness, paresthesias), visual disturbances (optic neuritis, blurred vision, diplopia, decreased visual acuity), cerebellar ataxia, dysarthria, facial palsy, bladder dysfunction (retention, incontinence), vertigo, seizures and changes in cognitive function (Boutin, Esquivel, Mayer, Chaumet, Ponson, & Arthuis, 1988; Bye et al., 1985; Cole & Stuart, 1995; Duquette, et al., 1987; Hanefeld, et al., 1991; Ghezzi, et al., 1997; Iannetti, et al., 1996; Pinhaus-Hamiel et al., 1998; Selcen, Anlar & Renda, 1996; Sindern et al., 1992). Many children present with more than one symptom (Boutin et al., 1988; Duquette, et al., 1987; Ghezzi, et al., 1997; Pinhaus-Hamiel et al., 1998).

**Inter-relapse symptoms**

Ongoing MS symptoms experienced by children are not well described in the literature. However, in addition to residual symptoms experienced during a relapse, adults with MS report a variety of pervasive symptoms including fatigue, heat and exercise intolerance, bowel and bladder dysfunction, cognitive changes, depression, spasticity, pain, tremor, and sexual dysfunction (Paty & Ebers, 1998; Morrison, 1999; Swingler & Compton, 1992). A majority of our pediatric patients complain of fatigue and heat intolerance, and three of our patients experienced seizures both during relapses and between relapses. Depression and tremor are less commonly noted symptoms. Many report difficulty in school performance, particularly with respect to short-term memory. Studies exploring cognitive impairment in adults with MS reveal that deficits in short-term memory, attention/information processing, executive functions (abstract reasoning, problem-solving, planning and self-monitoring), visual perception, and language, are present in many of these patients (Amato, Ponziani, Pracucci, Bracco, Siracusa, & Amaducci, 1995; Beatty, Goodkin, Monson, & Beatty, 1989; Fischer, [in press]; Rao, Leo, Bernardin, & Unverzag, 1991). Detailed neuropsychological testing in children with MS has not been reported.

**Treatment**

Although there is no cure for MS, a variety of therapies are used to treat acute relapses and manage symptoms. More recently, the availability of disease-modifying drugs that reduce the frequency and severity of exacerbation episodes have created new hope and options for individuals with RRMS. Unfortunately, these treatments have not been studied for safety and/or efficacy for patients under the age of 18. Despite this, studies indicating the need for early treatment lead clinicians to consider these treatment options for their young patients. Further study and the development of treatment guidelines are needed in the pediatric population.

**Treatment of acute relapse**

The most common treatment for acute relapses is corticosteroid therapy (Weinstock-Guttman & Cohen, 1996). High-dose IV methylprednisolone is used for patients with severe relapses that cause significant neurological impairment (Tsiris & Lisak, 1999; Weinstock-Guttman & Cohen, 1996). Steroids do not improve the ultimate degree of recovery, but do shorten the duration of the attack and hasten recovery from relapse symptoms (Paty, Hashimoto & Ebers, 1998; Weinstock-Guttman & Cohen, 1996). For patients with severe or life-threatening relapses unresponsive to corticosteroids, recent evidence suggests that plasma exchange should be considered (Weinshenker, O’Brien, Petterson, Noseworthy, Lucchetti & Dodick, 1999). Cyclophosphamide and IVlg may also be effective in certain patients. Additionally, precipitants of a relapse, such as an infection, should also be treated to enhance recovery (Weinstock-Guttman & Cohen, 1996).

**Disease modifying therapies**

Before 1993, no therapies were available for MS that altered the progression of the disease (O’Connor, 1998). Since that time, four immuno-modulating drugs have been released in Canada that reduce the number of relapses of patients with RRMS by about one-third (Tsiris & Lisak, 1999; Weinstock-Guttman & Cohen, 1996). Outcome studies of these drugs also demonstrate a reduction in the severity of relapses, progression of disability, and number of new and enlarging lesions on MRI; an increase in cognitive processing speed and flexibility, as well as visual memory; and an improvement in the visual evoked response (Paty, Hashimoto & Ebers, 1998; Weinstock-Guttman & Cohen, 1996). Unfortunately, none of these therapies reduce the current level of disability (Tsiris & Lisak; Weinstock-Guttman & Cohen, 1996). This finding supports the importance of treating patients early before permanent disability develops.

The immuno-modulating therapies currently available are interferon β-1a (Avonex®, Rebif®), interferon β-1b (Betaseron®) and glatiramer acetate (Copaxone®). They are administered as either a subcutaneous injection (Betaseron®, q2days, Rebif® 3x/week, Copaxone® 1x/day), or an intramuscular injection (Avonex® 1x/week). All of these drugs are expensive and can cost up to $21,000 per year. Most patients require financial assistance through extended health insurance or government programs to pay for therapy. The pharmaceutical companies (Berlex, Biogen, Serono, Teva Marion Partners) sponsor telephone support lines (Multiple Sclerosis Pathways™, The Avonex Support Line™, Multiple Support Program for Rebif®, Shared Solutions™) for assisting families with accessing financial resources to fund treatment. In addition, the help-lines provide information about the product and arrange for nurses to teach families how to administer injections.
The mechanism of action for interferons is complex. However, simply stated, they are believed to act as “sealants” that block lymphocytes from crossing the blood-brain barrier and therefore protect the CNS from autoimmune attack (O’Connor, 1998). The most commonly reported side effects of the interferons include transient flu-like symptoms (headache, fatigue, chills, myalgia, fever) and site reactions (redness, bruising, inflammation, pain, necrosis) (O’Connor, 1998; Tselis & Lisak, 1999; Weinstock-Guttman & Cohen, 1996). The flu-like symptoms begin within 24 hours of injection, last one to three days and tend to dissipate after two to three months. Other less commonly reported adverse effects include depression, spasticity, leukopenia, anemia, and abnormal liver enzymes, all of which resolve with a decreased dose or discontinuation of the drug (Weinstock-Guttman & Cohen, 1996). Although not routinely measured, up to 38% of patients will develop neutralizing antibodies which may decrease the efficacy of the drug (Tselis & Lisak, 1999).

**Glatiramer acetate** provides a different mechanism of action and side effect profile than the interferons. It is hypothesized that the T-cells that normally bind with myelin protein and produce inflammatory cytokines bind instead with glatiramer acetate and become anti-inflammatory (Teva Marion Partners, 1999; Weinstock-Guttman & Cohen, 1996). In addition to site injection reactions, a mild systemic post-injection reaction occurs in about 15% of patients involving flushing, chest tightness, palpitations, dyspnea, and anxiety (Tselis & Lisak, 1999; Weinstock-Guttman & Cohen, 1996). These symptoms tend to develop within minutes of the injection, last 30 seconds to 30 minutes, and resolve spontaneously without sequelae (Weinstock-Guttman & Cohen, 1996). They are not associated with myocardial ischemia.

Other treatments used to reduce exacerbation rate include azathioprine, cyclophosphamide, methotrexate, and mitoxantrone (Tselis & Lisak, 1999; Weinstock-Guttman & Cohen, 1996). The efficacy of these drugs is variable, and their side effect profile considerable, but may be used on an individual basis for severe and frequent relapses.

**Symptomatic treatment**

Patients with MS may experience a multitude of ongoing symptoms between relapses that cause differing levels of disability and impact on quality of life. There are several treatments and therapies available that offer varying degrees of symptom relief. Symptom management may involve patient education, rehabilitation, counseling, medication or surgery (Metz, 1998). The treatment choice is based on several factors which include: the patient’s needs, perceptions and expectations; the need to control symptoms in order to prevent complications; the degree to which the symptom is troublesome or worrisome to the patient; the family’s ability to afford and access the treatment; patient and family commitment to the intervention; and the potential side effects of the treatment (Metz, 1998). A detailed description of the treatment modalities for symptoms typically seen in MS is beyond the scope of this article.

**Development of a pediatric MS clinic**

In light of the complex nature of MS, the expanding availability of new MS treatments and the developmental needs of children, dedicated pediatric professionals who remain current in the ongoing developments in MS are required. Using a multidisciplinary approach, they can address health and developmental issues specific to children with MS and their families. Typically, children with MS are cared for by pediatric neurologists with limited experience in MS or adult neurologists with expertise in MS but lack of experience in dealing with the unique needs of children, youth, and their families. The neurologists and nurses caring for MS patients at The Hospital for Sick Children recognized the importance of developing a multidisciplinary team of health care professionals with expertise in pediatric MS. As a result, a pediatric MS clinic was created to provide comprehensive assessment, treatment, education, and support of children with MS and their families.

Before proceeding with the initiation of the clinic, health care professionals were identified who had an interest in developing their expertise in childhood MS. Subsequently, a dedicated team composed of a neurologist, clinic nurse, clinical nurse specialist, physiotherapist, and social worker was formed. Further support was sought from internal resources (psychology, psychiatry, neuro-ophthalmology, infectious diseases, pharmacy, neurophysiology) and external resources (St. Michael’s Hospital MS clinic, and the Multiple Sclerosis Society of Canada). Individuals from all of these services enthusiastically offered their support and expertise, and expressed their availability to provide care, consultation, and diagnostic investigation as needed.

Although many of the team members had experience caring for children diagnosed with MS, an initial task was to enhance the knowledge of all team members on recent issues in MS and MS-related care. This involved an extensive literature review, attendance at professional meetings, conferences and workshops, and consultation with experts in the field of MS. Fostering the expertise of all team members is an ongoing mandate.

A further step in implementing the clinic entailed accessing validated assessment tools and creating our own pediatric-focused assessment tools. For example, the modified fatigue impact scale, fatigue questionnaire and sleep questionnaire developed by the Multiple Sclerosis Council for Clinical Practice Guidelines (1998) were considered for examining fatigue and the impact of interventions. Similarly, the expanded disability status scale (EDSS) developed by Kurtzke (1983) was reviewed for measuring physical impairment and detecting changes in level of disability. As these scales and questionnaires are adult-focused, their validity or appropriateness for children was queried but felt to be worthy of testing. In addition, existing health history questionnaires, physical exam documentation forms and nursing assessment tools devised for adults with MS were reviewed and modified to address pediatric issues.
Another important task involved the compilation of educational material for patients, families and healthcare professionals. As a result of families approaching the MS Society for information about childhood MS in the past, the Toronto chapter developed, in consultation with The Hospital for Sick Children and parents, information packages for children and teens newly diagnosed with MS. These packages include a small pamphlet that describes MS in an age appropriate manner. The pharmaceutical company information kits and videos describing the immuno-modulating therapies were also obtained for review by patients and parents. Likewise, a hospital pharmacist was contracted to develop drug information fact sheets for families on the commonly used medications. As well, we collected pertinent articles and books to share with staff and families. A portable cart contains all of this information.

Planning the operationalization of the clinic was a vital step. Several issues required consideration, such as when and where the clinic would take place, who would attend each clinic, what assessments would be performed and by whom, and how care would be coordinated. Ultimately, we agreed that the clinic would take place once a month in the neurology clinic. The professionals attending each clinic were to include the neurologist, clinic nurse, clinical nurse specialist, the physiotherapist, and the manager of services from the Toronto chapter of the MS Society of Canada. The team physiotherapist would perform assessments on all children with signs of muscle weakness or motor deficits, or those requiring a baseline assessment of function and stamina. Team meetings were planned before and after the clinic to assist with the identification of other services requiring a referral or a request for attendance at a subsequent clinic. These meetings were also to be used to plan the assessments, discussion topics, and teaching required for the patients and their families. They were also used to determine which team members would perform the necessary assessments or address specific issues; and to coordinate a schedule for patients and team members to create an efficient flow of activity.

With planning complete and the date of the first clinic ascertained, the final step was to communicate the initiation of the pediatric MS clinic to professionals and parents. This involved sending a letter to pediatric neurologists, pediatricians, and adult MS centres requesting referral of pediatric MS patients. The team neurologist, clinical nurse specialist and clinic nurse also publicized the clinic’s creation through presentations to community physicians, neurologists, and other health care professionals. A notice of the clinic appeared in the hospital newsletter and in the MS Society newsletter.

Several months of consulting, information gathering, planning, accessing resources, creating assessment tools, collecting educational material and promoting the clinic culminated in the implementation of the first clinic in October 1999. To the best of our knowledge, this is the first MS clinic in North America dedicated to addressing the needs of children and adolescents with multiple sclerosis.
Nursing care of children and adolescents with MS

The nurse’s role in the care of pediatric MS patients is multifaceted and includes physical assessment (e.g., BP, weight, visual acuity), needs assessment, support, education, advocacy, referral and coordination. All care reflects the principles of family-centred care and focuses on the unique needs of children with MS and their families.

In addition to physical assessment, a pivotal nursing role is the assessment of the needs of children and their families with respect to the impact of MS on their daily lives. To guide our practice, we developed a nursing assessment tool that captures common issues seen in MS (e.g., fatigue, physical symptoms), as well as issues unique to the pediatric population (e.g., school performance, peer relationships, play and sports activities). Family coping; perceived needs regarding education, support, advocacy and referral; and the effect of the disease on activities of daily living are also addressed.

Support is a frequent need of both patients and family members. Families often view nurses as key sources of support within the health care system and approach them as primary contacts for support needs. Patient and family stressors such as functional loss, MS symptoms, hospitalization, uncertainty about relapses and rate of progression, and the chronic nature of the disease and its treatment require the provision of ongoing emotional and informational support by the nurse. Support may occur during a clinic visit, but also during a hospitalization or through telephone contact. Exploring other sources of support with families and linking them with patients and families experiencing a similar situation are further ways we try to meet their needs. Expressing availability as a contact person to provide support may also be beneficial to families.

Another important nursing role in the care of these patients is family education. Education needs are particularly high at diagnosis, when decisions are being made about treatment, when treatment is initiated and when new symptoms develop. Nurses provide and clarify information on a variety of topics related to multiple sclerosis including assisting families with their understanding of MS, reviewing symptom triggers, and explaining the variable course of the disease. Reviewing treatment options discussed by the neurologist; demonstrating medication administration and outlining pertinent points such as site rotation, frequency and time of injection, and sharps disposal; and discussing medication side effects and strategies for dealing with side effects (e.g., taking acetaminophen or ibuprofen to ease the flu-like symptoms associated with the interferon therapies) are also addressed by nurses caring for MS patients. Providing written educational material is essential to support verbal instruction.

For children with persistent MS symptoms or frequent relapses, advocacy may be required to ensure appropriate accommodation of needs at school. Issues such as mobility impairment, visual disturbances, and cognitive deficits may necessitate the addition of supports or adaptations for the child to continue to function at an optimal level within the school setting. Letters or personal contact with school personnel confirming the needs of the child and supporting the suitability of requested services and adaptations may be all that is needed to initiate a change. Similarly, nurses are in a key position to identify with the family the need for a referral to hospital services and resources (social work, psychiatry), rehabilitation centres, community rehabilitation services (OT, PT, speech, vision), the MS Society of Canada, or financial assistance programs. They may be responsible for making the referral directly, or facilitating the referral by a member of the health care team or the family. Once again, advocacy may be required for adequate access.

In our MS clinic, the above mentioned roles and responsibilities are shared between the clinic nurse and the clinical nurse specialist. In addition, the clinic nurse plays a coordination role with respect to facilitating flow of activity, initiating referrals, and ensuring that arrangements are made for desired tests and procedures. As well, a follow-up on needs identified during clinic or telephone discussions may be required by the nurse or other appropriate team member.

Future directions

Our pediatric MS clinic is still in its infancy, and we have many ideas on how we can improve the care we provide. For instance, we would like to produce a video geared to children and adolescents that reviews the current immuno-modulating therapies. Some of our patients have complained that they cannot relate to the “old people” (we think this means anyone over 25!) portrayed in the pharmaceutical company videos. To enhance adherence to therapy regimens, we want to include young people in the decision-making process as much as possible. We feel that information illustrated in a manner they can understand and associate with will help with this goal.

Other plans include further collaboration with the MS Society of Canada in the development of a support network for adolescents and parents, creating educational materials and identifying the need for educational/support sessions. As many of the assessment tools and scales we use are adult-focused, we would eventually like to modify or develop pediatric MS tools and scales to assist us with appropriate assessments including quality of life assessments for children with MS. Other long-term goals include developing a national database, and participating in childhood MS multi-centre treatment trials.

Summary

In summary, childhood onset MS is rare but may occur more frequently than originally believed. Although children present in a similar way to adults with MS, their needs and concerns are unique. With the development of our pediatric MS clinic, we now provide a multidisciplinary, family-centred approach to care that addresses the health and developmental needs of children and adolescents with MS. The clinic also fosters an environment conducive to enhanced expertise and understanding of an “adult” disease within a pediatric setting and creates opportunities for research into this relatively unknown area. Nurses collaborate with the team, and play a
significant role in the care of these children and their families through assessment, support, education, advocacy, referral and coordination of care. Although there is much more to be learned about pediatric MS, we feel that by focusing on the needs of these children, we will improve and optimize their care and outcomes.

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