

PEDIATRIC MS NURSING

Jennifer Boyd, RN, MHSc, CNN(C), MSCN
Clinical Nurse Specialist, Neurology
The Hospital for Sick Children
Toronto, Canada

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MS IN CHILDREN

- 5% of patients with MS are diagnosed before 18 years of age
- >95% present with relapsing-remitting course
- 50% with onset of MS before 16 years of age switch to SPMS after 23 years (Boiko et al, 2002)

DIAGNOSING PEDIATRIC MS

- Presenting symptoms similar to adults
- Children may have difficulty describing sensory or visual symptoms
- Children under 11 years:
 - have larger and more ill defined lesions on MRI
 - are more likely to present with encephalopathy and multifocal neurological deficits
- Pediatric MS added to the 2010 revisions to the McDonald Criteria (Pohlman, et al, 2011)

DIFFERENTIAL DIAGNOSES

- Mitochondrial disorder (Leigh disease)
- Metabolic disease, leukodystrophies
- Acute disseminated encephalomyelitis (ADEM)
- Infection (e.g., Lyme Disease)
- Lymphoma
- Inflammatory disease (SLE)
- Vasculopathies
- Vitamin deficiencies (B12)

IS PEDIATRIC MS INCREASING?

- ⦿ Enhanced awareness and monitoring
- ⦿ Improved diagnostic capabilities
- ⦿ Greater impetus to diagnose earlier in the disease process
- ⦿ Environmental influences
- ⦿ Lifestyle changes

IMPLICATIONS FOR NURSES

- ◉ More MS nurses and pediatric nurses now care for children and adolescents with MS
- ◉ Must consider the needs of this population and understand
 - developmental factors
 - psychosocial needs
 - parental involvement in care
 - issues with schooling
 - resources specific to pediatric MS
 - transition to adult care

DEVELOPMENTAL ISSUES

- Children are constantly growing and developing
- Dosing of medication often based on weight
- Approaches to care change at different developmental stages
- Care involves both the child and the family
- Suggest adult MS specialists collaborate with pediatric professionals to address developmental needs

CONCERNS OF CHILDREN AND TEENS WITH MS

- Ongoing symptoms
- Unpredictability and uncertainty of relapses
- Limitations to activities
- Having regular injections of medication
- Being treated differently
- Impact of MS on school performance and attendance

(Boyd & MacMillan, 2005)

EDUCATION AND SUPPORT OF CHILDREN

- Provide necessary and requested information at an age appropriate level
 - Re-educate periodically as they mature
- Recognize that many do not want a lot of information
- Encourage parents to capitalize on opportunities to provide education when their child asks questions
- Reassure they are not going to die

EDUCATION AND SUPPORT OF CHILDREN

- Encourage them to participate in their regular activities with adaptations as needed
- Provide guidance around dealing with fatigue and heat sensitivity
- Recognize that parents are a child's primary means of support
- Teens need some private time without parents during clinic visits
- Refer to a social worker, psychologist or psychiatrist at a pediatric facility if counseling needed

SUPPORTING PARENTS

- ◉ Initially, the parents are most burdened by the diagnosis
- ◉ Facilitating adaptation of the parents will facilitate adaptation of the child
 - Provide current, accurate information
 - Identify resources
 - Offer hope
 - Encourage access to personal sources of support
 - Refer for counseling as needed

EDUCATING PARENTS

- ⦿ Educate parents as the advocates and decision-makers for their children
- ⦿ Talk about disclosure of diagnosis to others
- ⦿ Discuss possible school issues

SCHOOL ISSUES

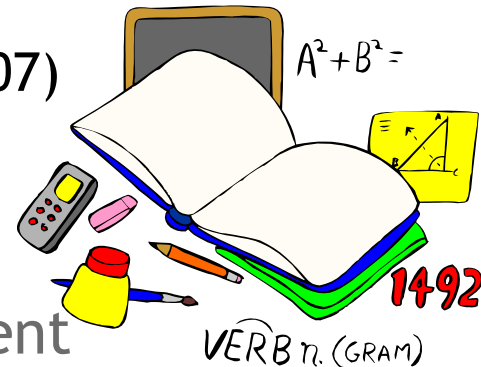
○ Cognitive Issues (MacAllister et al, 2007)

- Cognitive deficits common
- ↑ deficit with ↑ disease duration
- May struggle with school achievement
- May require academic supports
- Refer for neuropsychological testing

○ Fatigue - can affect academic performance, interfere with social activities and limit physical activity

○ Absenteeism

○ Communicating with school personnel

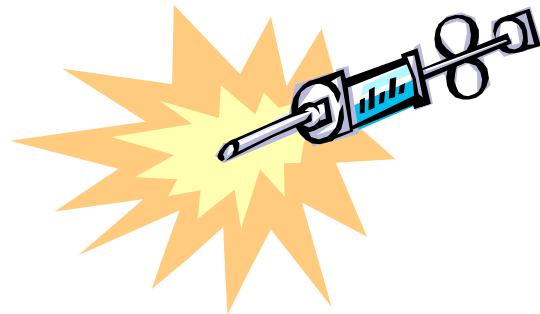


TREATMENT CHALLENGES

- Young children may not have the cognitive maturity to understand the rationale for injections and long-term benefits
- Adolescents do not always accept need for treatment
- Parents involved in the treatment decisions

DISEASE MODIFYING THERAPY (DMT) AND CHILDREN

- None of the DMTs have been systematically studied in children
- No clinical trials in pediatrics
 - efficacy, dosing issues
- DMTs not FDA approved for treatment of patients under age 18
- Found to be safe and commonly used in pediatric patients with RRMS (Chabas, et al, 2006)



CHOOSING A DMT FOR CHILDREN

- ◉ Involve the child in the discussion of treatment options
- ◉ Explore personal preferences
- ◉ Show the syringes, autoinjectors, etc.
- ◉ Allow handling of equipment
- ◉ Review previous experiences with needles
- ◉ Share others experiences with taking DMTs
- ◉ Encourage a “family” decision

INITIATING DMTS IN CHILDREN

- ⦿ Make the first injection a positive experience
- ⦿ Ensure the child has a full understanding of what is going to happen before giving the injection.
- ⦿ Give honest reassurance
- ⦿ Encourage participation of the child
- ⦿ Use a teaching doll for demonstration, practice and as an “ice breaker” or “comic relief”



INITIATING DMTS IN CHILDREN

- ◉ Identify coping strategies including comfort and distraction techniques
 - Listen to the views of the child and family to help tailor your approach
 - Develop a plan for implementing coping strategies (work as a team)
- ◉ Reduce injection discomfort by using a topical anesthetic cream/gel/spray, ice or heat
- ◉ Have the parent observe the nurse giving the first injection and role model a calm and confident approach

USE OF AUTOINJECTORS IN CHILDREN

- ◉ Most children under the age of 12 are fearful of the autoinjectors
- ◉ Ensure they are aware of the sound and sensation of the autoinjector deploying
- ◉ Counsel parents on the potential need to give manual injections to younger children
- ◉ Poor tolerance of the autoinjector may make adherence challenging and lead to an ongoing unpleasant experience for both child and parent

RESOURCES FOR FAMILIES

○ National Multiple Sclerosis Society

- Children and Teens with MS: A Network for Families
 - Parent Teleconferences (guest speakers)
 - Email Support Group (parents and teens)
 - Kids Get MS Too: A Guide for Parents Whose Child or Teen has MS
 - Mighty Special Kids - booklet (age 6-12)
 - Students with MS & the Academic Setting: A Handbook for School Personnel
 - Managing School-Related Issues: A Guide for Parents with a Child or Teen Living with MS
 - MS Learn Online - Pediatric MS series

PEDIATRIC MS CENTERS OF EXCELLENCE

- 6 centers throughout US supported by NMSS
 - Birmingham, AL
 - Boston, MA
 - Buffalo, NY
 - Rochester, MN
 - San Francisco, CA
 - Stony Brook, NY
- offer comprehensive services by multidisciplinary teams of pediatric and adult MS experts
- evaluate and address school and other psycho-social issues, and support families

OTHER SUPPORTS

⦿ Teen Adventure Camp

- 4 days at a camp in Rhode Island
- Ages 11-18
- www.pediatricmscenter.org

⦿ Summer Adventure Camp

- One-week camp in Canada (eastern Ontario)
- Ages 8-21
- www.mssociety.ca



SUGGESTED READING

- ◉ Boyd, J.R. & Milazzo, M.C. (2011). Working With the Pediatric Patient Diagnosed With Multiple Sclerosis. In: J. Halper & N.J. Holland (Eds.), *Comprehensive Nursing Care in Multiple Sclerosis*, 3rd Edition (pp. 193-213). New York: Springer.
- ◉ MacAllister, W.S., Boyd, J.R., Holland, N.J., Milazzo, M.C., Krupps, L.B. (2007). The psychosocial consequences of pediatric multiple sclerosis. *Neurology*, 68(16, suppl. 2), S66-S69. (Pediatric Multiple Sclerosis and Related Disorders supplement)
- ◉ Boyd, J.R. & MacMillan, L.J. (2005). Experiences of Children and Adolescents Living with Multiple Sclerosis. *Journal of Neuroscience Nursing* 37(6), 334-342.