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Children with Multiple Sclerosis and Nursing Care Approach

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Abstract

Multiple sclerosis is a chronic and progressive disease proceeding with inflammation, demyelination, and degeneration in the central nervous system. Multiple sclerosis is rarely seen in childhood, but it can occur more frequently than it is known in early childhood. Children with multiple sclerosis disease may reach disability levels at an earlier age than adults. Therefore, early diagnosis, optimal treatment, and care management of multiple sclerosis emerging in childhood are important. The goals of this treatment and care management are similar to those of adult multiple sclerosis; however, there are some specific concerns related to pediatric multiple sclerosis. The concerns related to the efficacy and safety of immunomodulatory treatments used by pediatric multiple sclerosis patients, the continuation of the neurodevelopmental process in children, the pharmacokinetic and pharmacodynamic differences between pediatric and adult multiple sclerosis patients, the interruption of school life of children, and anticipatory anxiety of children and their families are among the major concerns. In this traumatic and challenging process, meeting the physical, emotional, cognitive, and social needs of children and their families is very important for disease management and for the adaptation of children to the disease. In light of this information, the aim of our review article is to give information related to multiple sclerosis disease in childhood and to explain the nursing approach to this disease.

Keywords: Pediatrics, multiple sclerosis, nursing, treatment, care

Introduction

Multiple sclerosis (MS) is a chronic and progressive disease that progresses with inflammation, demyelination, and degeneration processes in the central nervous system. Pediatric MS (diagnosed <18 years of age) constitutes 3.5%-5% of all MS cases and its incidence varies between 0.2 to 0.64/100000.[1-5]

Early diagnosis and optimal management of pediatric MS patients are important because children in this age group face significant physical disability at an earlier age than adults.[6-8] In addition, pediatric patients have a worse cognitive prognosis than adult patients.[6] However, this rapid progress can be slowed down with early treatment and care management.

No previous study has been found in the literature in the field of pediatric nursing regarding the subject of our review article. In light of this information, it was aimed to provide information specific to childhood MS and to discuss the nursing approach in our study.

Epidemiology

Although research on pediatric MS is limited, it is known that the disease dates back to the 19th century.[9] Jean-Martin Charcot, a French neurologist, first described MS in adults in the 1800s.[9] In Charcot's studies, it was observed that pediatric MS was characterized by signs of tremor, ataxia, and speech disorder, and the first documented pediatric MS case in 1887 was an 8-year-old child.[1] In the same study, the autopsy of the child and his mother, who had similar symptoms, was examined, and changes were found in the spinal cord and neurons.[1] With subsequent scientific studies, 59 children with pediatric MS were described for the first time in 1902. Until 1980, 136 pediatric MS cases were reported in the literature. After these years, the number of pediatric MS patients has increased in parallel with the rapid development of diagnostic methods.[1,7,10]

Multicenter cohort and prevalence studies show that between 1.7% and 5.6% of the MS population is younger than 18 years of age.[6,11,12] In general, it is known that the incidence

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of pediatric MS is higher in children aged 13-16 years.[12] In a study conducted by Belman et al[11] with 490 pediatric MS patients, it was stated that there was no gender difference for children with MS diagnosed under the age of 10. However, as the frequency of symptoms and age at diagnosis increased, the female gender was significantly dominant, especially in the adolescent group. Multiple sclerosis, which begins before puberty, is more complex because clinical, radiological, and cerebrospinal fluid examination findings may be different in adolescents.[5,13]

In the study conducted by Yılmaz et al[7] with 193 pediatric patients from Turkey, it was stated that the female gender was dominant in more than half of the patients. This periodic difference detected suggests the effects of hormones in the pathophysiology of MS.

The epidemiology of MS also differs according to geographical regions. It has been determined that the disease shows different distributions in studies conducted in different communities and regions.[14-16] These racial and ethnic differences also affect the frequency and clinical course of the disease. For example, the incidence of the disease increases in individuals living in areas far from the equator, while MS is not seen in American Indians, it is frequently encountered in European races.[14,15]

Etiological Factors

Many theories try to explain pediatric MS when we look at scientific studies.[13,17-20] In light of current information, it is stated that many factors play a role in the etiology of pediatric MS. The interaction of genetic and environmental factors often causes pediatric MS. Findings suggestive of genetic predisposition have been identified in studies. In addition, exposure to Epstein–Barr virus (EBV) among viral infections is thought to play a role in the etiology of MS.[12] In a multicenter study by Banwell et al.[17] 137 MS patients and 96 healthy control patients were compared, and it was reported that EBV serum positivity was correlated with a 3-fold higher risk of MS. As a result of the study, they developed the theory that B cells infected with EBV pass into the brain and cytotoxic T lymphocytes damage astrocytes in brain tissue.[17]

Another factor that plays a role in the etiology of MS is vitamin D deficiency. Vitamin D, a powerful immunomodulator, is activated by sunlight. In a study by Nielsen et al.[18] it was stated that low vitamin D deficiency in the neonatal period might be effective in developing pediatric MS. In addition, other studies in the literature prove that vitamin D deficiency is effective in the development of MS.[19,20]

In recent years, multicenter studies specific to the etiology of pediatric MS have compared maternal and perinatal characteristics of adolescents with and without MS disease.[21,22] In the study of Graves et al.[21] it was stated that while maternal age, body mass index, and breastfeeding duration are not among the etiological factors, cesarean delivery, socioeconomic level, and ethnicity play a role in the development of MS. Other factors that play a role in the etiology of pediatric MS are known to be environmental factors such as heavy metal toxicity, obesity, exposure to chemicals, and cigarette smoke.[1,21,22]

Clinical Course

The clinical course of MS was specified by Lublin et al[23] as 3 clinical courses: clinically isolated syndrome (CIS), relapsing MS, and progressive MS.[23] Among these basic clinical courses, the increase in disease activity (the patient has an attack, the lesion activity in magnetic resonance) or the progression of the disease has been influential in the formation of the clinical course of the disease.[24]

Clinically Isolated Syndrome

The first neurological picture in which the patient showed clinical findings in the form of isolated optic neuropathy, medulla spinalis involvement, hemispheric involvement, and brainstem syndrome and symptomatic or asymptomatic lesions suggestive of MS on magnetic resonance imaging (MRI) was defined as CIS.[16,24]

Benign Multiple Sclerosis

It is a clinical course that does not leave serious sequelae and progresses with less frequent attacks, and a low lesion load is detected in MRI and diagnosed later.[24]

Relapsing-Remitting Multiple Sclerosis

It is a clinical course that progresses with acute attacks and shows complete or almost complete recovery. There is no progression of the disease between attacks. It has 2 sub-clinical courses, active relapsing-remitting multiple sclerosis and non-active relapsing-remitting multiple sclerosis.[24]

Progressive Multiple Sclerosis

It is the clinical course in which disability is seen during the disease. After an average of 5-6 years of relapse with periods of attacks and remissions, a secondary progressive period is observed, with a decrease in the number of attacks, less improvement, and a progressive increase in disability. There are 5 sub-clinical courses: the active, the progressive active, the non-progressive non-active, the progressive non-active, and the non-progressive (stable disease).[24]

Active Disease

It is a picture in which some attacks show complete or almost complete recovery or leave a function or tissue dysfunction, and a new lesion develops with contrast enhancement on T1 imaging or hyperintense on T2 imaging.[24]

Patients with the radiologically isolated syndrome clinical course were not shown as the MS phenotype because they did not show clinical signs and symptoms.[16,23,24]

Clinical Features

As members of a multidisciplinary team, nurses must be familiar with the clinical features of MS and the needs of the patient and family to succeed in care management. Clinical features in children are similar to adults, but brain stem and cerebellar involvement is more prominent.[24]

Table 1 describes the common findings in MS.[16,25]

Treatment

Multiple sclerosis is rare in childhood. However, it may occur more frequently than is known in the early period.[1,4] Treatment of the disease aims to prevent the occurrence of an attack, accelerate recovery after the attack, and prevent the progression of the disease or neurodegeneration.[25] In previous studies, the use of drugs for MS in children and adolescents was not studied in clinical trials, and the safe dose ranges were based on experimental and observational studies in adults.[4] Currently, the majority of immunomodulatory drugs that change the course of the disease in pediatric MS have

Table 1. Clinical Features of Children with Multiple Sclerosis

Fields	Symptoms
Somatosensory	It is the most common finding. Impairment of vibration and provision sense, galena, and Lhermitte
Motor	Loss of motor power (monoparesis, hemiparesis, paraparesis, tetraparesis), stiffness in the legs, spasticity and increased muscle tone, abnormal reflexes, and increased resistance with passive movements
Brainstem	Nystagmus, vertigo, peripheral facial paralysis, and speech disorder
Visual	Optic neuritis, vision loss, photophobia, and pain
Cerebellar	Gait ataxia, trunk ataxia, intentional tremor, and dysdiadochokinesia
Cognitive/ psychiatric	Impaired memory, attention, concentration, problem-solving ability, and fatigue
Urinary	Urgency, infection, and incontinence
Paroxysmal	Diplopia, ataxia, dysarthria, trigeminal neuralgia, and tonic and hemifacial spasm

been approved by the European Medicines Agency for MS patients over 12 years of age.[26] Currently, Fingolimod is the only treatment approved by the US Food and Drug Administration for pediatric MS patients.[27] However, other treatments such as interferons, glatiramer acetate, dimethyl fumarate, teriflunomide, natalizumab, rituximab, and cyclophosphamide are also currently used for pediatric MS patients.[3,26-28]

Disease-modifying therapies for MS can prevent attacks from occurring and delay poor progression. These therapies include subcutaneous injections of interferon beta-1a 3 times a week, intramuscular injections of interferon beta-1a once a week, subcutaneous injections of interferon beta-1b every day, and subcutaneous injections of glatiramer acetate 3 times a week.[26] A common characteristic of these treatments is the presence of injection-related side effects during the early stages of the treatment, injection site reactions, and a negative impact on the child's development throughout the treatment.[4,26,29]

Treatment and Care Difficulties

Pediatric MS guidelines recommend starting treatment from the early stage of the disease.[3,24,26,28] It is crucial that an experienced specialist starts the treatments, that the child and his family are followed regularly, and that nursing care is provided.[30] Adaptation to treatment is a challenging process for pediatric MS patients. For this reason, pediatric nurses have essential roles and duties in determining the difficulties experienced by children and families in treatment, adapting to treatment, and coping with existing problems.[11,29]

The goals of treatment and care for pediatric MS are similar to those of adult MS, but there are concerns specific to pediatric MS apart from these goals.[29] Concerns about the efficacy and safety of the immunomodulatory treatments used by pediatric MS patients, the continuation of the neurodevelopmental process in children, the existence of pharmacokinetic and pharmacodynamic differences compared to adults, the interruption of children's school life, and the anxiety of children for the future are among these concerns.[1,26,31]

Identifying different neurodevelopmental repair mechanisms specific to pediatric MS patients, directing patients to effective treatment options, providing age-appropriate education, and meeting their physical, emotional, cognitive, and social needs facilitate adaptation to the disease.[2,26]

Nursing Care Approach

Multiple sclerosis is a degenerative and progressive chronic disease. Having a progressive chronic disease in childhood, including adolescence, is difficult for a child. During this period, the child and his family enter a long and tiring treatment process.[32,33] Having a progressive chronic illness causes the following difficulties in the lives of the child and the family:

- Frequent hospital visits of children,
- Experiencing treatment-related side effects,
- Interruption of school life,
- The disease is progressive,
- Families experiencing financial difficulties,
- Parents' feelings of inadequacy and self-blame,
- Restrictions in daily activities.[1,11,34]

With the diagnosis of MS in the child, a difficult process begins for the child and the family, and this process develops suddenly.[1] Children and their families stated that they experienced uncertainty, stigma, sudden attack development, and intense anxiety that could negatively affect treatment management and compliance.[29]

Diagnosis and treatment processes put a burden on children and families in many ways. Children and their families need to be supported with an appropriate nursing approach.[33-35] Considering the developmental period of pediatric patients with MS, the development of the child, the presence of chronic disease, depression, anxiety, eating disorders, and the high tendency of adolescents to risky behaviors have been identified as significant risk factors.[36] In this period of life, pediatric patients meet new and unfamiliar phases of life characterized by emotional changes as well as new responsibilities and leave their childhood behind. Therefore, in the nursing approach to the child diagnosed with MS and his/her family, the child should be handled together with his/her family. Nurses should take appropriate initiatives to facilitate the adaptation of children with chronic diseases to treatment and disease. For this reason, nurses should not forget that the most critical requirement is to maintain a relationship with healthcare providers while regulating the lifestyle of the child with chronic disease and her family.[34] Families aim to communicate collaboratively with healthcare professionals to exchange information and use an interactive form of problem-solving. For this reason, families expect their caregivers to form a bond with their children and show genuine care.[11,34] The nursing approach aims to empower families to raise and care for their children and maximize their abilities in this regard.[34,37] In addition, supporting the intellectual development of children, improving self-management and decision-making skills, and facilitating the transition from pediatric clinic to the adult clinic should be included in nursing initiatives.[38]

Conclusion

In our study, scientifically based information about MS in childhood is given, and the nursing approach to MS is explained. The pediatric nurse has the responsibility to provide high-quality and uninterrupted care. When providing nursing care for a child with MS, nurses should collaborate with different health disciplines with a holistic approach

that includes the child and his family. In pediatric MS patients, the most important nursing interventions are to start immunomodulatory treatments in a timely and appropriate dose, to use school support systems, to make cognitive assessments of children, to apply symptom management related to the disease and treatment, and to encourage children to adapt to the disease and treatment.

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