

## PEDIATRIC SCHOOL PSYCHOLOGY

### Lyme Disease: Etiology, Neuropsychological Sequelae, and Educational Impact

By R. A. Hamlen & D. S. Kliman

School psychology publications contain few articles on the impact of Lyme disease on the capacity of school-aged children to function successfully within an educational program. This oversight is of considerable concern, as the school psychologist can be a front-line consultant for assistance with a child or adolescent presenting with sequelae of vague behavioral, cognitive, learning and/or psychological problems. The focus of this article is to highlight the importance of the school psychologist to recognize impaired school performance due to undiagnosed Lyme disease, act as the child's advocate within the medical and school community, and assist in the design of a supportive educational environment for the ill child.

#### Disease Overview

Lyme disease is a multi-system infection caused by the spirochete *Borrelia burgdorferi* that is generally transmitted to humans from rodents through the bite of a deer tick (*Ixodes scapularis*, *I. pacificus*) (CDC, 2004). The bite often is unnoticed due to the small, poppy-seed sized tick. The initial indications of infection can include a reddish rash, fever, chills, fatigue, joint pain, headache, stiff-neck, mental confusion, and sleep disturbance. Misdiagnosis of initial symptoms and delayed treatment can lead to debilitating chronic illness with musculoskeletal, cognitive, and neuropsychiatric impairments (Cameron, 2003; Halperin, 2004; Shadick et al., 1994; Tager & Fallon, 2001). Symptoms are multivariate and often have puzzling presentation in some patients, especially children (Fallon et al., 1998).

#### Infection incidence and risk

Lyme disease is the fastest growing U.S. insect-vector disease, with a 40% increase in the Centers for Disease Control (CDC) surveillance cases from 2001 to 2002 (23,763 cases) (CDC, 2004). This trend continued in 2005 with a 36–84% increase relative to 2004 reported for northeastern and mid-Atlantic states (CDC, 2006). Under-reporting is acknowledged by the CDC (2000) and is a particularly troublesome issue based on incidence of pediatric cases (Dedeoglu & Sundel, 2003; Shapiro & Seltzer, 1997; Young, 1998).

• Headaches and neck stiffness
• Neuropathy (nerve pain) in back, legs or hands
• Paresthesia (tingling sensation, often in legs and hands), facial paralysis (Bell's palsy), tinnitus, and sensory hyperacusis (unusual sensitivity to sound or light)
• Deficits with memory — short-term, sequential, spatial, and tracking, slowness of word and name retrieval.
• Decreased reading comprehension and handwriting skills
• Impaired speech fluency — stuttering and slurred speech
• Inability to accurately perform previously mastered mathematical calculations
• Vision problems — difficulty in the classroom in seeing and following visually presented material, and frequent blinking or tics, inability to coordinate eye movement — targeting difficulties, and distorted visual images
• Musculoskeletal (movement) and coordination impairment, balance problems (clumsiness or vertigo)
• Executive function impairment — inability to activate or sustain effort and attention, and manage frustration; confusion, and thinking sluggishness in expressing thoughts
• Frequent errors in speaking, writing, spelling, or dyslexic-like behaviors (errors in letter and number reversals).
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• Severe and chronic fatigue unrelieved by rest — falling asleep in class, missing class due to tiredness, and sleep disturbance
• Emotional and uncharacteristic behavioral presentation — withdrawal from peers or shift to a lower functioning group, depersonalization (loss of a sense of physical existence), cessation of involvement in sports or other extra-curricular activities, inattentiveness, attention deficit behavior, obsessive-compulsiveness, depression, anxiety, panic, aggression, defiance, explosive outbursts, mood swings, irritability, hyperactivity, nightmares, and sudden suicidal thoughts
• Inability to perform at grade level — inconsistency or sloppy school work, late assignments, decline in grades, being overwhelmed by schoolwork, missed school days, and school phobia

<sup>1</sup> Adams et al., 1994; Berenbaum, 2004; Coyle 2002; Fallon et al., 1998; Gordon, 2000; Halperin, 2004; Juchnowicz et al., 2002; Pietrucha, 2001; Peltonmaa et al., 1998; Rachman & Garfield, 1998; Sherr, 2000, 2002; Shotland et al., 2003; Tager & Fallon, 2001; Tager et al., 2001.

Lyme disease occurs nationwide; however, twelve states — Connecticut, Delaware, Maine, Maryland, Massachusetts, Minnesota, New Hampshire, New Jersey, New York, Pennsylvania, Rhode Island, and Wisconsin — account for 95% of cases reported nationally (CDC, 2004).

People of all ages are vulnerable to Lyme disease, and significant infection rates occur in children ages 5 to 14 years (CDC, 2004). Children in endemic suburban residential areas surrounded by deer tick-infested woods are at significant risk of infection. Each spring the risk increases appreciably as temperatures reach 40° F, when deer ticks become active and outdoor activities increase (Lane et al., 2004).

#### Diagnosis

A central diagnostic difficulty responsible for the current debate within the medical community regarding diagnosis and treatment of Lyme disease (Hamlen, 2004; Stricker and Lantin, 2003) is the lack of a definitive and readily available laboratory test for active infection (Donta, 2002; Tylewska-Wierzbanska & Chmielewski, 2002). Physicians are challenged to diagnose early infection based on clinical presentations (patient history, exposure risk, and symptoms) using testing data, including those for co-infections, as supporting evidence for the diagnosis (Krause et al., 2002). The CDC (1997), FDA (1999), and the National Institute of Allergy and Infectious Diseases/NIAID (2001) have acknowledged the commercially available serology tests are not sufficiently sensitive for diagnosis, warned of the overdependence on test results in diagnosis and treatment decisions, and stated that a clinical diagnosis is necessary. Diagnosis is especially difficult when the rash is absent (Steer et al., 2003), serology is negative (Kaiser, 2000), uncharacteristic symptoms occur (based on physician experience), and atypical neuropsychiatric symptoms are present (Tager & Fallon, 2001). The task of separating a primary psychiatric disorder from the neuropsychiatric sequelae of Lyme disease can be daunting. Single photon emission tomography (SPECT), positron emission tomography (PET), magnetic resonance imaging (MRI), and neuropsychological testing may be required to make a differential diagnosis (Fallon et al., 1997; 2003).

#### Physical and Neuropsychological Sequelae in Children

Cognitive symptoms are a direct result of dysfunction of the cerebral cortex where cognitive processing occurs (Bransfield et al., 2001). While children with Lyme disease can experience a plethora of symptoms, it is generally the *subtle* neurological and cognitive deficits that have eluded prior detection. These deficits have the most profound negative impact on a child's school performance and social life (Table 1).

Every child with Lyme disease has a unique profile of symptoms which can vary significantly during the process of infection. In addition to the previously described neurological and cognitive deficits readily identifiable by the school psychologist, additional presenting sequelae that may be detected during a student interview are listed in Table 2.

Presenting sequelae	Reference
<i>flu-like illness</i> — fever and chills	CDC, 1997
<i>gastrointestinal manifestations</i> — chronic gastritis, duodenitis, and colitis	Fried et al., 1999
<i>cardiac complications</i> — irregular rhythm and heart block	Karadag et al., 2004; Lo et al., 2003
<i>ocular defects</i> — optic neuritis, neuropathy, conjunctivitis, uveitis, keratitis, ocular pain, and decreased vision or loss	Mikkila et al., 2000; Rothermel et al., 2001
<i>rheumatologic symptoms</i> — arthritis, myalgias, arthralgias, and musculoskeletal pain	Shadick et al., 1999

Any of the symptoms in Tables 1 and 2 can indicate undiagnosed Lyme disease and it should be considered when unusual changes in behavior or academic performance are noted. Frequently, symptoms develop in a child who previously performed well within the school environment. A most challenging manifestation of Lyme disease is that symptoms may persist, or they may be *episodic* and *fluctuating* in type and severity, further confusing diagnosis as the child may not appear sick in the traditional sense (Berenbaum 2004; Smith, 2004). Disease onset may be gradual with increasing fatigue, social disinterest, or deteriorating school performance (Fallon et al., 1998). An important finding is that cognitive and behavioral difficulties are similar to those observed with affective, oppositional defiant, and attention deficit disorders (Healy, 2000; Ramirez, 2003; Tager et al., 2001). Further complicating diagnosis is the inability of children and teenagers to express their feelings to parents or friends (Lang, 1997).

Children generally are not diagnosed initially with psychiatric manifestations of Lyme disease because their complaints are seen as indistinct and functional in nature. If the undiagnosed disease process has psychiatric manifestations that lower the child's frustration tolerance and/or increase irritability and impair cognitive functioning, a referral from the school or treating physician to a psychiatrist to address an assumed psychogenic or functional disorder is likely (Fallon et al., 1998). While much of the data on psychiatric illness in children due to Lyme disease are anecdotal, 60% of confirmed Lyme disease adult patients reported an episode of major depression during their illness, 90% for the first time in their life (Fallon & Nields, 1992; Rachman & Garfield, 1998).

In cases where facial paralysis (Bell's palsy) was the initial symptom of infection and when appropriately treated with antibiotics, the neuropsychologic, cognitive functioning, and general health outcomes (based on neuropsychologic tests) were comparable to those who did not have Lyme disease (Adams et al., 1999a; Vazquez et al., 2003). Where initial symptoms were a skin rash or cognitive impairment, studies also indicated significant

recovery with treatment (Adams et al., 1999b; Nowakowski et al., 2003; Wang et al., 1998). However, Bloom et al. (1998) reported that in patients with *late* neurologic manifestations of Lyme disease, improvement was often gradual or they presented with continuing neurocognitive symptoms requiring I-V antibiotic therapy. Pediatric cases with significant clinical deterioration have been documented by clinicians (Shapiro & Seltzer, 1997; Young, 1998). The specific reasons why some children suffer severe deficits is unknown. However, children whose diagnosis and treatment were delayed and who displayed considerable impairment had significantly more school-related cognitive and psychiatric sequelae compared to healthy children (Tager et al., 2001). Unfortunately, there are children who remain ill for months or years who have been seen by several physicians who erroneously labeled the child as hypochondriacal, psychosomatic, depressed, or malingering (Berenbaum et al., 1999; Bernbaum, 2004; Healy, 2000; Pietrucha, 2001).

**Educational Concerns: How Can the School Psychologist Help?**

Although most school nurses are alert to the impact of Lyme disease on school-aged children (Healy, 2000; Kyle-Louise, 2001; McSweegan, 2001; Rudd-Arieta, 2003), information on this disease is generally absent from school psychology publications. As a front-line consultant to the educational team, the school psychologist should have a basic understanding of Lyme disease diagnosis and treatment and be able to recognize and articulate the impaired school performance frequently caused by this illness.

There are few phenomena addressed by school psychologists that are as emotionally and clinically challenging as cognitive deterioration of children (Shaw, 2005). Understanding the origin of the cognitive decline is essential for the school psychologist to determine the type of deterioration the child is most likely experiencing and to define the rehabilitation, education accommodations, and parental and sibling support needed. The Pediatric Index of Skill Change (PISC) instrument is a possible tool for identifying and understanding the nature of cognitive deterioration (Shaw, 2005).

The school psychologist has a role as a post-diagnosis student advocate and active participant in the school and medical management of the student's illness. School psychologists can serve as a sounding board for parents through listening and giving support and encouragement. There also is a need for follow-up skill assessment to monitor effectiveness of educational accommodation and medical treatment. The school psychologist can play a pivotal role in ensuring that the ill child is not left behind, but instead able to function to the best of her/his ability (Berenbaum, 2004; Smith, 2004).

Federal law, i.e., Section 504 of the Federal Rehabilitation Act of 1973, the Americans with Disabilities Act (ADA) of 1990, and the 1993, 1997, and 2004 Individuals with Disabilities Education Acts (IDEA) mandate that students with disabilities in elementary, secondary, and post-secondary schools receiving federal financial assistance not be discriminated against because of their disabilities. In many cases schools are required to provide accommodations or supportive individual educational programs to help ill students achieve their academic goals (Betz, 2001; Boyce et al., 2000). Accommodations include

shortened days, untimed tests, dropping unnecessary requirements, alternative testing methods, separate/quieter testing locations, and modified home instruction programs (Msall et al., 2003). As educational personnel may not be familiar with the physical, neurological, and emotional ramifications of Lyme disease in the school setting, the school psychologist in cooperation with the school nurse and special education teacher can provide insight about the illness and educational accommodations (Cavendish, 2003).

**Conclusions**

Because Lyme disease can be difficult to diagnose, schools can be the best settings to observe the neuropsychological sequelae secondary to the disease. Whenever a change in a child's behavior, mood or overall functioning occurs, Lyme disease should be considered as a possible etiology (Fallon et al., 2006). School psychologists, nurses, and teachers need to be aware of the symptoms and course of Lyme disease as they possibly can be the first to identify an underlying infectious cause of aberrant student behavior.

Lyme disease has become a permanent part of America's public health landscape, impacting most perilously its young patients as well as their families and the medical and school communities. All children seriously affected by Lyme disease have alteration in personality, cognitive functioning, and behavior (Sherr, 2002). Undiagnosed, chronic Lyme disease is avoidable and the school psychologist has a key role, as a member of the multidisciplinary team, to conduct a thorough assessment and differential diagnosis, assess skill loss, and develop effective educational and other therapeutic techniques. ♦

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