Lyme Disease: Etiology, Neuropsychological Sequelae, and Educational Impact

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

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ymptoms of Lyme disease 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).

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 psychological 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).

Table 1. Neurological and cognitive symptoms in children with undiagnosed Lyme disease

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Reference</th>
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<tbody>
<tr>
<td>Headaches and neck stiffness</td>
<td>CDC, 1997</td>
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<tr>
<td>Neuropathy (nerve pain) in back, legs or hands</td>
<td>Fried et al., 1999</td>
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<tr>
<td>Paresthesia (tingling sensation, often in legs and hands)</td>
<td>Fried et al., 1999</td>
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<td>Deficits with memory — short-term, sequential, spatial, and tracking, slowness of word and name retrieval</td>
<td>Fried et al., 1999</td>
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<td>Decreased reading comprehension and handwriting skills</td>
<td>Fried et al., 1999</td>
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<tr>
<td>Impaired speech fluency — stuttering and slurred speech</td>
<td>Fried et al., 1999</td>
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<tr>
<td>Inability to accurately perform previously mastered mathematical calculations</td>
<td>Fried et al., 1999</td>
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<tr>
<td>Vision problems — difficulty in seeing and following visually presented material, and frequent blinking or tics, inability to coordinate eye movement — targeting difficulties, and distorted visual images</td>
<td>Fried et al., 1999</td>
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<tr>
<td>Musculoskeletal (movement) and coordination impairment, balance problems (clumsiness or vertigo)</td>
<td>Fried et al., 1999</td>
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<tr>
<td>Executive function impairment — inability to activate or sustain effort and attention, and manage frustration; confusion, and thinking sluggishness in expressing thoughts</td>
<td>Fried et al., 1999</td>
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<td>Frequent errors in speaking, writing, spelling, or dyslexic-like behaviors (errors in letter and number reversals)</td>
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<td>Severe and chronic fatigue unrelated by rest — falling asleep in class, missing class due to tiredness, and sleep disturbance</td>
<td>Fried et al., 1999</td>
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<tr>
<td>Emotional and uncharacteristic behavioral presentation — withdrawal from peers or shift to a lower functioning group, personalization (loss of a sense of physical existence), cessation of involvement in sports or other extra-curricular activities, inattentiveness, attention deficit behavior, obsessive-compulsive behavior, depression, anxiety, panic, aggression, defiance, explosive outbursts, mood swings, irritability, hyperactivity, nightmares, and sudden suicidal thoughts</td>
<td>Fried et al., 1999</td>
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</tbody>
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Table 2. Presenting sequelae documented for Lyme disease

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<th>Symptom</th>
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<tr>
<td>Flu-like illness — fever and chills</td>
<td>CDC, 1997</td>
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<tr>
<td>Gastrointestinal manifestations — chronic gastritis, duodenitis, and colitis</td>
<td>CDC, 1997</td>
</tr>
<tr>
<td>Cardiac complications — irregular rhythm and heart block</td>
<td>CDC, 1997</td>
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<tr>
<td>Ocular defects — optic neuritis, neuroophathy, conjunctivitis, uveitis, keratitis, ocular pain, and decreased vision or loss</td>
<td>CDC, 1997</td>
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<tr>
<td>Rheumatologic symptoms — arthritis, myalgias, arthralgias, and musculoskeletal pain</td>
<td>CDC, 1997</td>
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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 (Berenson et al., 2004; Smith et al., 2004). Severe and chronic fatigue may at times be gradual with onset of 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., 2003). 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 psychological 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).
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-Louis, 2001; McSweeney, 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 so 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 the 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.

References


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