Pediatric Disorders

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Current Topics *and* Interventions *for* Educators

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Lyme Disease and Tick-Borne Infections*

Causes and Physical and Neuropsychological Effects in Children

Ron Hamlen and Deborah S. Kliman

Caroline's parents brought her to a psychologist because, rather suddenly, she was presenting with a variety of behaviors unusual for her. Caroline, aged 9, had always been an excellent student, cooperative, and eager to learn. She was rather shy and serious in manner, and her passions were reading and horseback riding.

Within the month previous to her first session with the psychologist, Caroline's interest in all things related to school had waned dramatically. She often asked if she could stay home. She seemed generally lethargic and no longer showed much interest in reading, taking trips to the library, or playing with her friends. Perhaps most alarming to her parents was Caroline's refusal to continue her riding lessons. She was frequently distractible or "off in her own world," both at home and in school, and was often found napping in her room.

Caroline was also demonstrating increasingly anxious behaviors. For example, she worried that something bad would happen to her parents, worried that her friends did not want to play with her, stated that her teachers did not like her anymore, and expressed fear she would be hurt while riding. None of these had ever been her concerns previously.

(Continued)

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(Continued)

She had undergone a complete physical examination, including some blood work, and her pediatrician could find nothing amiss. Her psychologist suggested a trial of antidepressant medication, but Caroline's parents were reluctant to go this route.

Caroline's parents were at a loss to think of any triggering incident that might have prompted the behaviors described. Is this young girl depressed? Suffering from an anxiety disorder? Or is there an as yet undiagnosed organic cause? What clues in Caroline's presentation might have led an educator to suspect Lyme disease and/or an associated tick-borne infection? If blood tests do not confirm a diagnosis of a tick-borne disease, then what would be the most appropriate course of action and treatment? Assuming that Caroline does have a tick-borne disease, what do her teachers and other school support personnel need to know, and how can they best support Caroline and her parents during her course of treatment?

INTRODUCTION

Education publications contain few articles on the impact of Lyme disease and associated tick-borne infections on the capacity of school-aged children to function successfully within an educational program. This oversight is of considerable concern, as educators are front-line service providers for children and adolescents presenting with symptoms of behavioral, cognitive, learning, and/or psychological problems. Educators can play a significant role in recognizing impaired school performance due to Lyme disease or other tick-borne infections and advocate for the child within the medical/school community.

BACKGROUND

Lyme disease (LD) and associated tick-borne infections (TBIs) are multisystem diseases caused by the following bacteria: *Borrelia burgdorferi* (Lyme disease spirochete), *Ehrlichia* and *Anaplasma* species (rickettsial bacteria), *Bartonella* species (bacterium), *Mycoplasma* species (bacterium), Southern tick-associated rash illness (STARI; a spirochete), and *Babesia* species (a protozoan parasite). These infectious microorganisms are generally transmitted to children from rodents or small mammals by the attachment and feeding of a deer tick or a lone star tick. The nymphal tick, whose attachment is responsible for causing the majority of infections, is the size of a poppy seed and often goes unnoticed.

The initial indications of LD infection can include but are not limited to a reddish rash, flulike illness (fever and chills), fatigue, joint pain, headache, stiff neck, mental confusion, and sleep disturbance. A single tick may transmit several of these microorganisms in the same attachment, and several of the coinfections may present with symptoms similar to those of LD. Although the risk of coinfection differs by geographic location, every tick attachment has the potential of transmitting multiple infections (Swanson, Neitzel, Reed, & Belongia, 2006). In addition, the LD spirochete

possesses molecular survival strategies, enabling it to evade the immune response and to persist in its human host (Rupprecht, Koedel, Fingerle, & Pfister, 2008). Misdiagnosis and delayed treatment frequently lead to debilitating chronic illness with relapses and deterioration, especially in musculoskeletal, cognitive, and neuropsychiatric impairments (Fallon, Kochevar, Gaito, & Nields, 1998; Halperin, 2004). Symptoms often have puzzling presentation in patients, especially in children (Fallon et al.).

Although some school nurses are alert to the impact of LD and associated TBIs on school-aged children (e.g., Healy, 2000), information on these diseases is generally absent from the education and psychology literature. Educators require a basic understanding of the diagnosis and treatment of TBIs. They must also be able to recognize and articulate the impaired school performance frequently caused by these illnesses and advocate for the student with illness within the school, family, and medical communities.

Infection Incidence and Risk

Lyme disease is the fastest-growing vector-transmitted disease in the United States, with a 38% increase in the Centers for Disease Control surveillance cases from 2006 to 2007 (CDC, 2007; 2008). Roughly 20,000 new cases of LD are diagnosed each year, and the CDC (2007) acknowledges underreporting. This is particularly troublesome because of the incidence of pediatric cases (Young, 1998).

Lyme disease is endemic in the Northeastern and mid-Atlantic states, in the upper North-Central region, and in northern California. 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, 2007). Lyme disease has been documented in every state, and associated TBIs are reported in the same geographical areas as LD.

People of all ages are vulnerable to LD, and significant infection rates occur in children aged 5 to 14 years (CDC, 2007). Children in suburban residential areas surrounded by tick-infested woods and those who participate in outdoor recreational activities are at the greatest risk of getting LD or other TBIs. Infection can occur from childhood activities in a shady home environment, especially where ground cover, moist humus, and leaf litter dominate play areas (Klein, Eppes, & Hunt, 1996). Each spring, the risk of infection increases significantly; as temperatures reach 40°F (4.5°C), ticks become active, and outdoor activities increase (Lane, Steinlein, & Mun, 2004). Although every tick might not be infected, every tick attachment has the potential for transmitting LD and associated TBIs.

Diagnosis

The central diagnostic difficulty responsible for the current debate within the medical community on diagnosis and treatment of LD and TBIs is the lack of definitive and readily available laboratory tests for active infection (Coulter et al., 2005). Physicians are challenged to diagnose early TBIs based on clinical presentations (patient history, exposure risk, and

symptoms). Laboratory test data, including those for coinfections, can be supportive in diagnosis (Sherr, 2004). The Food and Drug Administration (FDA; Brown, Hansen, Langone, Lowe, & Pressly, 1999) has questioned the reliability of commonly marketed LD test kits and stated that they "should **never** be the primary basis for making diagnostic or treatment decisions" (p. 1). The CDC (2007) has commented that test data based on CDC LD surveillance case definition, as reported with the test kits, is not to be used in diagnosis and treatment decisions. Both the CDC and FDA have acknowledged that a clinical diagnosis is the "best practice." No test can rule out the possibility of infection (Coulter et al., 2005). School psychologists and nurses, educators, pediatricians, and primary care physicians need to be aware of the occurrence rates, potential severity, and diagnostic dilemmas of all TBIs. With our mobile society, this is true in both TBI-endemic and nonendemic areas.

Neurological and Cognitive Deficits

Lyme disease is characterized by a strong pro-inflammatory response, which can involve the brain, and an aberrant innate pro-inflammatory response, which is involved in chronic illness (Rupprecht et al., 2008). Cognitive symptoms are a direct result of dysfunction of the cerebral cortex where cognitive processing occurs (Bransfield, Brand, & Sherr, 2001). Although children with LD and TBIs can experience a variety of symptoms, it is often the subtle neurological and cognitive deficits, which may elude detection, that have the most negative effect on a child's school performance and social life. Children with multiple TBIs frequently present with more diverse and severe symptoms compared to children with LD alone (Swanson et al., 2006).

These symptoms should be red flags for unrecognized LD and associated TBIs:

- Headache (can be severe), neck stiffness
- Peripheral neuropathy (nerve pain) in back, legs, or hands; musculoskeletal pain (can be severe)
- Distal paresthesia (tingling sensation, often in legs and hands) and facial paralysis
- Deficits with short-term memory, including with sequential, spatial, and tracking tasks; slowed word and name retrieval, letter and number reversals
- Decreased reading comprehension and handwriting skills
- Impaired speech fluency, including stuttering and slurred speech
- Inability to perform accurately previously mastered mathematical calculations
- Vision problems, including difficulty in the classroom in seeing and following visually presented material, frequent blinking or tics, inability to coordinate eye movement, and targeting difficulties
- Movement and coordination impairment, balance problems, clumsiness, or vertigo
- Executive function impairment, including the inability to activate or sustain effort and attention or manage frustration, confusion and lethargic thinking, and difficulty expressing thoughts

- Frequent errors in speaking, writing, spelling; dyslexic-like behaviors
- Severe and chronic fatigue unrelieved by rest, which may be evidenced by falling asleep in class; missing class because of sleep disturbance and/or sporadic night sweats
- Emotional and uncharacteristic behavioral presentation, including withdrawal from peers or a shift to a lower-functioning group, depersonalization (loss of a sense of physical existence), cessation of involvement in sports or other extracurricular 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, which may be evidenced as inconsistent or sloppy schoolwork, late assignments, lower grades, feeling overwhelmed by schoolwork, missed school days, and school phobia
- Other neurological manifestations, including tinnitus, trigeminal neuralgia, facial numbness, sensory hyperacusis (unusual sensitivity to sound), photophobia, and intrusive and distorted visual images

Every child with LD or TBIs has a unique symptom profile that varies significantly during the process of infection. In addition to declining cognitive ability and declining school performance, additional presenting physical symptoms include gastrointestional manifestations, such as chronic abdominal pain, gastritis, duodenitis, and colitis (Fried, Abel, Pietrucha, Kuo, & Bal, 1999); and cardiac complications, such as irregular rhythm, carditis, and heart block (Chen, 2008). In addition, ocular symptoms, including optic neuritis, neuropathy, conjunctivitis, uveitis, keratitis, ocular pain, or vision loss, are common (Rothermel, Hedges, & Steere, 2001).

Developmental Delay, Attention Disorders, and Autism Spectrum Disorders

Clinical experience suggests that in a subset of pediatric patients, LD and TBIs can mimic developmental delay and autism spectrum disorders (Bransfield, Wulfman, Harvey, & Ysman, 2008; Bransfield, 2009; Nicolson, 2007). Cognitive and behavioral difficulties are also similar to those observed in affective, oppositional defiant, and attention deficit disorders (Tager et al., 2001). Infection can also exacerbate pre-existing behavioral or psychiatric illness (Bransfield, 2007).

Depressive, Panic, and Aggressive Disorders

Rarely are children initially diagnosed with psychiatric manifestations of LD or TBIs, because their complaints are vague and thought to be 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, then a referral from the school or treating physician to a psychiatrist addressing the assumed psychogenic or functional disorder is likely (Bransfield, 2007). Although much

of the data on psychiatric illness in children due to LD and TBIs is anecdotal, 60% of confirmed LD adult patients reported an episode of major depression during their illness (Rachman & Garfield, 1998). Moreover, significant numbers of hospitalized psychiatric patients were found seropositive for *B. burgdorferi* relative to healthy comparison subjects (Hajek et al., 2002). Clinical experience suggests a link between TBIs and aggression in children and adolescents (Bransfield, 2001).

Long-Term Outcomes

When facial nerve palsy was the initial symptom of LD and appropriately treated with antibiotics, neuropsychological and cognitive functioning and general health outcomes (based on neuropsychologic tests) were comparable to those in patients who did not have LD (Vazquez, Sparrow, & Shapiro, 2003). With initial dermatological or neurological symptoms, studies also indicated significant recovery (Adams, Rose, Eppes, & Klein, 1999). However, Bloom, Wyckoff, Meissner, and Steere (1998) reported that in patients with late neurologic manifestations of LD, improvement was often gradual or with continuing multiple neurocognitive symptoms requiring IV antibiotics. Adolescents with a history of treated LD can be at risk for long-term problems in cognition and school functioning (McAuliffe, Brassard, & Fallon, 2008).

IMPLICATIONS FOR EDUCATORS

Educators address few phenomena that are as emotionally and clinically challenging as diagnosing the cause of a child's cognitive deterioration (Shaw, 2005). When pediatric TBIs are diagnosed early and treated promptly, few children develop long-term cognitive deficits (Vazquez et al., 2003) or require significant educational services. However, some children remain ill even after appropriate treatment (Berenbaum, 2004; Bransfield et al., 2001; McAuliffe et al., 2008). Often these children have had symptoms for months or years and been seen by several physicians who have erroneously labeled the child hypochondriac, psychosomatic, depressed, or malingering (Healy, 2000). The school psychologist and educator should perceive the symptoms as red flags when conducting intelligence testing, curriculum-based assessments, and direct student observation. Educators should play a multifaceted role in the identification of this illness by interviewing parents, as well as teachers or child care workers from previous years, to compare past with current performance. In addition, the school psychologist can be a postdiagnosis student advocate and active participant in the school and community medical management of the student's illness. Follow-up skill assessment to provide discrete data to audit the effects of educational accommodation and progress of medical treatment is necessary.

Section 504 of the Rehabilitation Act of 1973, the Americans with Disabilities Act (ADA) of 1990, and the 2004 Individuals with Disabilities Education Act (IDEA) mandate that students with disabilities in elementary,

secondary, and postsecondary schools receiving federal financial assistance cannot be discriminated against because of their disabilities. In many cases, schools are required to provide accommodations and/or supportive individual educational programs to help ill students achieve their academic goals (Betz, 2001). Accommodations include shortened days, untimed tests, the dropping of unnecessary requirements, alternative testing methods, separate/quieter testing locations, and modified home instruction programs (Msall et al., 2003).

IDEA obliges school districts to identify disabled and potentially disabled children and refer them to a Child Study Team, on which the school psychologist is an active member, to develop an Individualized Educational Program (IEP), monitor the IEP, and revise the IEP as needed (Boyce, Gelfman, & Schwab, 2000). Children with Lyme disease or TBIs should lead as full and normal a life as possible, given the severity of their illness. They are covered under Section 504, ADA, and IDEA legislation.

Because educational personnel may not be familiar with the physical, neurological, and emotional ramifications of LD or associated TBIs in the school setting, the school psychologist, in cooperation with the school nurse and special education teacher, can provide insight about the illness and needed educational accommodations (Cavendish, 2003).

Whenever a change in a child's behavior, mood, or overall functioning occurs, including a suspected attention deficit/hyperactivity disorder, LD or TBIs should be considered quickly, as delays in diagnosis are associated with chronicity and morbidity (Fallon et al., 1998). Children and adolescents with LD who display considerable impairment and whose diagnosis and treatment are delayed have significantly more school-related cognitive and psychiatric sequelae than healthy children (McAuliffe et al., 2008; Tager et al., 2001). School psychologists, educators, nurses, and teachers may be the first adults with an opportunity to recognize the possible underlying infectious origin of presenting symptoms.

Effects of LD and TBI include fatigue, school tardiness, memory problems, distractibility, attention difficulties, and inability to understand complex information. These children also have behavioral disorders (e.g., irritability, anxiety, and depression) and school performance deterioration. Less is known about the long-term outcome for children with coinfections, as less research has been published. Clinical experience suggests that when the coinfections are effectively treated before treating LD, the outcome is favorable. Untreated coinfections, however, can lead to chronic illness, often involving severe neurological and cognitive problems.

EDUCATIONAL STRATEGIES

- Communicate with parents and, with appropriate permission, medical professionals concerning the child's medical status. Educators can provide important information to physicians and parents on changes in academic performance, social and emotional functioning, and eating habits.

- Being flexible with assignments is critical. Children with LD or TBIs often have fluctuating levels of attention and alertness.
- Plans for itinerate homebound instruction may be necessary when children are not able to attend school.
- Allowing additional time for assignments may be necessary.
- Other strategies include shortened days, untimed tests, the dropping of unnecessary requirements, alternative testing methods, separate/quieter testing locations, and modified home instruction programs

DISCUSSION QUESTIONS

1. What features are common to presentations of uncharacteristic behavioral and cognitive symptoms in school-aged children with Lyme disease or other tick-borne infections?
2. Are tick-borne diseases endemic, common, or rare in your location?
3. Why might blood and laboratory tests be unreliable in detecting tick-borne diseases?
4. Why might it be difficult to distinguish the symptoms of a tick-borne illness from behavioral and cognitive symptoms from other causes?
5. What other commonly diagnosed conditions may present symptoms similar to those of a tick-borne illness?
6. What consequences does delayed treatment have for children with a tick-borne illness?

RESEARCH SUMMARY

- Lyme disease and tick-borne diseases are common and often underdiagnosed.
- Lyme disease and tick-borne diseases have widely varied symptoms, including changes in cognitive and behavioral functioning.
- There are no clear laboratory tests for the diagnosis of Lyme and tick-based diseases. The diagnosis is made clinically on the basis of presenting symptoms.
- Several medical conditions have clinical symptoms similar to those of Lyme disease, making diagnosis extremely difficult.
- Treatment for Lyme disease can be challenging. The organism causing Lyme disease can lie dormant and then become active again at a later time. However, when treatment is effective, cognitive functioning, health status, and emotional functioning often return to preinfection levels.

RESOURCES

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HANDOUT

PEDIATRIC LYME DISEASE AND ASSOCIATED TICK-BORNE INFECTIONS

Whenever a change in a child's behavior, mood, or overall functioning occurs, including a suspected attention deficit/hyperactivity disorder, Lyme disease (LD) or tick-borne infections (TBIs) should be considered quickly as delays in diagnosis are associated with chronic impairment. Parents and educators need to be aware of the possibility of LD and TBIs as they may be first to recognize the possible underlying infectious origin of aberrant student behavior. Lyme disease and TBIs have become a permanent part of America's public health landscape, affecting most perilously its young, their families, and school community. Many children seriously affected by these infections have alterations in personality, cognitive functioning, and behavior.

Infection Incidence and Risk

- Lyme disease is the fastest growing vector-transmitted disease in the United States with about 20,000 new cases reported each year.
- 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.
- People of all ages are vulnerable to LD, yet significant infection rates occur in school-aged children.
- Children in endemic suburban residential areas surrounded by tick-infested woods and those who participate in outdoor recreational activities are at risk of getting LD and associated TBIs. Even the city child on a nature outing is at risk with the greatest potential for infection in the spring.

Overview of Diseases

Lyme disease and TBIs are multi-system bacterial and protozoan diseases. These disease-causing microorganisms are transmitted to humans from rodents or small mammals through the attachment and feeding of a deer tick or a lone star tick. A single tick may co-transmit several of these microorganisms in the same attachment, which is often unnoticed due to the small, poppy seed-sized tick. Initial indications of infection can include but are not limited to a reddish rash, flu-like symptoms (fever, chills), fatigue, joint pain, headache, stiff neck, mental confusion, and sleeping disturbance. Symptoms are complex and often have puzzling presentations in children. An individual can have LD and TBIs repeatedly.

Diagnosis

Physicians are challenged to diagnose early TBIs based on clinical presentations (patient history, exposure risk, and symptoms). Laboratory test data are of limited reliability, identifying only about 50% of infections. A large body of clinical evidence illustrates that diagnosis of LD is especially difficult when the rash is absent, laboratory tests are negative, uncharacteristic symptoms occur (based on physician experience), and/or atypical psychiatric symptoms are present. The task of separating a primary pediatric psychiatric disorder from psychiatric LD and certain TBIs can be daunting and brain imaging technologies and psychological testing may be required. Misdiagnosis and delayed treatment of TBIs frequently lead to debilitating chronic illness and cognitive impairments.

School Performance

Every child with LD or TBIs has a unique profile of symptoms, which can vary significantly during the process of infection. Although children with TBIs can experience a plethora of symptoms, it is often the

subtle multiple cognitive and neurologic deficits that elude prior detection. These deficits have the most profound negative impact on a child's school performance and social life.

Frequently symptoms develop in a child who previously performed well within the school environment. A challenging manifestation of TBIs is that symptoms may persist or they may be episodic and fluctuating in type and severity, further confusing diagnosis. Based on teacher or parental observations, the child may not appear sick in the traditional sense. Disease onset can be gradual with increasing fatigue, social disinterest, or deteriorating school performance. An important finding is that multiple cognitive and behavioral difficulties are similar to those observed with affective, oppositional defiant, attention deficit, and possible autism spectrum disorders. Further complicating diagnosis is the inability of children and teenagers to express their feelings to parents, teachers or friends.

Children are not initially diagnosed with psychiatric manifestations of TBIs because their complaints are seen as vague and inconsequential. If the undiagnosed disease has psychiatric manifestations, then a referral from the school or treating physician to a psychiatrist is likely.

What Can Parents and Educators Do?

- The most important action for parents is to prevent infection. Many universities and public health departments can provide information on tick repellants, protective clothing, high risk areas and behaviors to avoid, landscape chemical applications, and tick control on pets.
- However, if symptoms and school problems occur due to LD or other TBIs, it is imperative that parents and teachers collaborate, in consultation with a school psychologist and/or nurse to take appropriate medical intervention. Effective parent/teacher communication is crucial to discuss events in the home and school life, the problems they encounter, and feelings that result. It is vital for the parents and school to monitor the ill child's behavior, assessing positive and negative changes, and communicating these observations.
- Parents and educators can be post-diagnosis advocates and active participants in seeking necessary school accommodations. Frequently, children with LD or associated TBIs and who struggle to remain in school hear comments from their classmates (often behind their back) about their "drama" and that they are just faking for attention. This experience can be devastating to the child's emotional stability and parents and teachers need to support the child and raise awareness in the school community.
- Federal law, that is, Section 504 of the Federal Rehabilitation Act of 1973, the Americans with Disabilities Act (ADA) of 2000, and the 2004 Individuals with Disabilities Education Act (IDEA), mandates 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 needed accommodations and/or supportive Individualized Educational Programs (IEPs).
- Accommodations include shortened days, un-timed tests, dropping unnecessary requirements, alternative testing methods, separate/quieter testing locations, and modified home instruction programs. Children with Lyme disease should lead as full and normal a life as they are capable of given the severity of their illness.

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Chapter 10

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