

Lyme disease symptoms present challenges



The threat of Lyme disease is particularly relevant in New England. Leo J. Shea, Ph.D. is chairman emeritus of the National Research Fund for Tick-Borne Diseases, Inc. He is a clinical assistant professor at New York University Medical Center and has a private practice in Quincy, Mass. (photo by Tom Croke)

By Ami Albernaz

Mood disturbances, difficulty concentrating, impaired cognitive processing - all are symptoms that can be linked to an array of diagnoses. Yet some psychologists argue that one possible culprit is often overlooked, setting unknown numbers of people on ineffectual courses of treatment. The culprit: Lyme disease.

Just as physicians might mistake Lyme disease for multiple sclerosis, Lou Gehrig's disease or chronic fatigue syndrome, psychologists might misdiagnose it as attention deficit disorder, Tourette's syndrome or chronic fatigue syndrome, says Leo J. Shea, Ph.D., chairman emeritus of the National Research Fund for Tick-Borne Diseases, Inc.

The threat of Lyme disease is particularly relevant in New England, most which is deemed high or moderate risk by the Centers for Disease Control and Prevention. Though Lyme disease can be effectively treated with antibiotics, it can cause chronic joint ache and neurological problems if undiagnosed.

Identifying Lyme disease is tricky because "no one has been able to come up with a gold standard for diagnosis or for treatment," says Shea, who is also a clinical assistant professor of rehabilitation medicine at New York University Medical Center and maintains a private practice in Quincy, Mass. While tests for antibodies to the spirochete bacteria that cause the illness do exist, they are not foolproof. A person who has recently been bitten by a tick may not produce antibodies for a few weeks, resulting in a false negative. People with compromised immune systems may not produce antibodies at all. Additionally, the symptoms of Lyme disease, such as memory impairment, subtle deficits in visual processing and fatigue, can be non-specific.

Practitioners suspecting Lyme disease often are left to piece together a diagnosis based on the patient's history. "What we would look for is whether there was a clear point in time at which things changed," Shea says. If this is the case, he might recommend a test for Lyme disease; if the patient is lucky, the test will come back positive and it will be early enough for antibiotics to treat it. Without a diagnosis - even if Lyme disease is suspected - physicians may be hesitant to prescribe long courses of antibiotics for reasons including potential drug resistance.

For patients in this category, understanding what is wrong with them is an exercise in frustration. Sheila Statlender, Ph.D., a clinical psychologist practicing in Newton and

Cambridge, Mass., says she gets as many as three or four calls per week from people concerned that they or a child might have the illness. She sees both children and adults, and currently her practice includes a number of bright, high-functioning teenagers who suddenly began experiencing cognitive difficulties.

She notes one patient who is now 45 and had been a top student in high school before she began struggling, rather suddenly, with attention and cognition problems. She was treated for depression and anxiety, but now traces the problems back to a high school camping trip during which she was bitten by a tick.

For Statlender, helping people who have Lyme disease stems from hard-earned personal experience. All three of her children have had the illness and all received a series of misdiagnoses after they fell ill. The three exhibited different symptoms including slowed processing speed and impaired concentration, gastrointestinal problems, joint and muscle pain and extreme fatigue. Though they are now better, "it's a work in progress," Statlender says.

Neuropsychological testing can inform the sorts of interventions and accommodations that could be helpful for patients struggling with Lyme disease, she says. Children and teens experiencing new or intensified academic challenges might benefit from educational accommodations, while adults find that they may experience new difficulties at work and at home performing tasks that they previously were able to do well.

"It's not unusual to hear some of them express the fear that they are developing early Alzheimer's," Statlender says. "It is important to include both timed and untimed [cognitive] testing to get an accurate idea of their current potential. What's needed is better awareness of the neuropsychological symptoms which can be associated with Lyme disease, along with appropriate support and flexibility."

Patrick McAuliffe, Ph.D., who helped facilitate a support group for teens with Lyme disease in Wilton, Conn., agrees. McAuliffe, who is now an adjunct assistant professor of psychology at Teachers College at Columbia University, says that not only is there controversy over the exact cause of the cognitive and behavioral disturbances sometimes associated with Lyme, but there's also "a lack of good, solid research on what helps kids [with cognitive problems that might be linked to Lyme disease] in school.

"You can look at IQ and achievement, though oftentimes that's not broad enough when more subtle deficits might be driving the problems," he says. "The better that the schools can test the entire range of functioning, the better the interventions can be. There's a lot of individual variability."

Meanwhile, efforts toward a more definitive Lyme disease test continue. The National Research Fund for Tick-borne Diseases has raised more than \$1 million toward this end, which Shea says has been made possible by the group's membership comprising doctors and researchers with diverging views on Lyme disease.

"We just want the best possible research and the way to get that is by having a range of ideas represented," Shea says, adding that he is hopeful that someday, people will not have to suffer the consequences of not having the illness detected early on.

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