

Lyme Disease Treatment Standards and Children

by Lorraine Johnson, J.D., M.B.A.

Lyme disease is a bacterial infection typically transmitted by the bite of a tick, although transplacental transmission has been shown to occur in some cases. Twenty-five percent of reported Lyme disease cases are children. In addition to Lyme disease, ticks may transmit a number of other diseases, including anaplasmosis, babesiosis, bartonellosis, and ehrlichiosis, which make the disease more difficult to treat. The symptoms of Lyme disease mimic a number of other diseases and disorders and include a wide variety of musculoskeletal, cardiac, neurologic, neuropsychiatric and cognitive symptoms. When treated promptly, the disease responds well to treatment. However, when the diagnosis is delayed, as is frequently the case, the disease may progress to its chronic form that is more difficult to eradicate and less responsive to treatment.[1]

Parents of children who are seriously ill with the persistent form of Lyme disease need to navigate a host of complex medical decisions. Problems may arise when state, school, or other authorities involved with the child have insufficient information about the problems associated with the diagnosis and treatment of chronic Lyme disease or the existence of two standards of care. Because of these misunderstandings, parents sometimes find themselves involved with child protection agencies or school districts filing inappropriate charges of child abuse or neglect.

By law, parents are granted the "primary role" in the "upbringing of their children".[2] In the absence of child abuse or neglect, a child's parents have the exclusive authority to determine the proper course of medical care and other issues concerning the child's welfare. While the legal definitions defining the nature and scope of child abuse and neglect vary from state to state, all child protection statutes are intended to protect children from serious harm within the family.

Mandatory reporting laws imposed on educators and health care providers combined with low "reason to suspect" standards and sanctions for failure to report, necessarily result in a system-wide bias towards false reporting. [3] In 1997, approximately two-thirds of all child abuse investigations were determined to be unsubstantiated.[3] The Herculean task set for those involved in child protection and welfare is to balance the competing goals of protecting children from harm and protecting innocent parents, children, and families from damaging investigations and disruptive separations. The gravity of the alleged offense should play a large role in determining whether or not to pursue a claim.[3] Potential conflicts-of-interest and bias that may underlie charges must also be considered. While the role of the disgruntled ex-spouse in instigating child abuse allegations is more widely recognized, claims by insurers, physicians, or school districts may be prompted by more subtle professional bias or economic incentives (e.g., avoiding expensive diagnostic tests, treatment, or educational accommodations) or just lack of knowledge about Lyme disease.

Inappropriate allegations of child abuse or neglect in Lyme disease cases typically arise when school or medical facilities are not familiar with the two standards of care or the complex presentation of persistent neurologic Lyme disease in children. The optimum antibiotic regimen and duration of treatment for chronic Lyme disease has not yet been determined, and two standards of care have arisen for the diagnosis and treatment of chronic Lyme disease.[1] Both standards of care are reflected in peer reviewed evidence-based guidelines posted on the National Guidelines Clearinghouse sponsored by the U.S. Department of Health and Human Services, which also provides a summary of the two standards and a comparison chart.[4-6] The guidelines promulgated by the Infectious Diseases Society of America (IDSA) advocate short-term treatment approaches and rely heavily on laboratory tests for diagnosis.[7] In contrast, the guidelines promulgated by the International Lyme and Associated Diseases Society (ILADS) promote longer term treatment based on the patient's response to treatment and relegate laboratory testing to a supporting role.[8] Significant specialty bias exists between the two treatment approaches such that a diagnosis or treatment plan based on one standard of care is frequently repudiated by physicians following the other standard of care.

The polemic nature of the debate between treatment approaches and the specialty bias that permeates the treatment of persistent Lyme disease can create conflicts between parents (particularly divorced parents), between parent and school district, and between the parent and child protection services agencies. Hence, it is critical for those involved in the child's education and protection to understand the two standards of care, who is entitled to choose between treatment options, and what constitutes child abuse or neglect.

The United States Supreme Court has held that patients have a fundamental right to make medical decisions and control what happens to their own body under the concept of patient autonomy.[2] Children are regarded as lacking the capacity for making these decisions on their own, and generally parents make medical decisions on their behalf. Although the presumption of parental control over the child is very strong, the state may intervene under the doctrine of *parens patriae* in very limited circumstances to protect the welfare of the child, primarily when the child is being abused or neglected. [9] The U.S. Department of Health and Human Services explains the deference to parental judgment in medical treatment matters as follows:

The decision to provide or withhold medically indicated treatment is, except in highly unusual circumstances, made by the parents or legal guardian ... This is the parents' right and responsibility ... The parents' role as decision maker must be respected and supported unless they choose a course of action inconsistent with applicable standards established by law. [10]

The United States Supreme Court agrees that "absent a finding of neglect or abuse,... [parents] retain plenary authority to seek ...care for their children." [2]

When two standards of care exist regarding the treatment of a child's medical condition, the selection between the available treatment options belongs to the parents. The treatment of the child in accordance with any approach within the medical standard of care is "consistent with applicable standards established by law" and does not constitute child abuse. Child abuse in the medical context (e.g., Munchausen by Proxy) requires an element of intentionality and deception. In short, the parent or parents must be fabricating symptoms in the child with full knowledge that the child does not have the condition.[11, 12] Absent this level of culpability, the parents' right to make medical decisions for a minor child cannot be abrogated by teachers, schools, child protection agencies, or even other physicians who disagree with the treatment selection made. Moreover, respect for the parents' fundamental right to make autonomous medical decisions on behalf of their child means that allegations of child abuse must be evaluated in accordance with the standard of care selected by the parents and that any physician consultations reflect the standard of care selected by the parents. In the context of 504 and IDEA accommodations, the school district should be sensitive to the standard of care selected by the parents.

Disagreements between parents regarding treatment may arise when parents are divorced. The parent who has sole custody generally is entitled to make medical treatment decisions unilaterally, while medical decisions are shared when there is joint custody.[13] Disputes should be resolved like any other child custody dispute, with resort to the judicial system if necessary.[13] There is a growing trend toward including minor children in the decision making process. For instance, the American Academy of Pediatrics recommends obtaining consent from children 13 or older. Moreover, the United Nations Convention on the Rights of the Child requires that the child's views be given "due weight" "according to the age and maturity" of the child.[2] Some states recognize and grant "mature minors" treatment decision rights as well. [9, 14] Hence, based on the maturity of the child, those involved in resolving disputes between the parents may consider the viewpoint of the child. *When disputes arise in the course of treatment, treatment should be continued pending resolution of the dispute to avoid disruption of the treatment plan as part of maintaining the status quo.*

In summary, the selection between legitimate medical treatment options does not constitute child abuse. Care should be taken to ensure that child abuse claims are evaluated in accordance with the medical standard of care selected by the parent, bearing in mind the considerable specialty bias that may exist among physicians regarding the diagnosis and treatment of tick-borne diseases. When parents disagree, resolution may require judicial intervention as in other custody disputes. Finally, those involved in determining the validity of child abuse or neglect claims need to be mindful of the potential personal, professional, or economic conflicts-of-interest or biases that may underlie child abuse claims.

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