

Centers for Disease Control Study: The Social and Economic Impact of Lyme Disease in School Children



Background by Pat Smith, President, LDA

Background: In March 1992, LDA president Pat Smith was invited to the DC office of Congressman Christopher Smith (NJ) to present to officials from the National Institutes of Health and the Centers for Disease Control and Prevention (CDC) information on how Lyme disease impacts school districts. These officials included Duane Gubler, ScD, CDC, Director, Division of Infectious Diseases and David Dennis, MD, MPH, Lyme Disease Program Director. Pat, at the time a Wall Township (NJ) school board member, presented a compilation of data gathered from nine school districts in NJ. The data included children on home instruction, teachers with Lyme, home instruction costs related to Lyme disease, and costs of treatment (actual cost, insurance payment, and family cost). As a result of her presentation, the CDC visited NJ and selected five of the nine districts for an intensive study, beginning with CDC meetings in Pat's district which at the time had 55 Lyme cases. Pat helped the CDC develop some of the study parameters and aided in district cooperation.

The draft CDC school district study was completed but never published despite intense efforts on Pat's part to make that happen. Study information however, was presented to a packed house in an October 1992 Wall Township Congressional meeting on Lyme disease hosted by Congressman Smith where Mr. Gubler,

Dr. Dennis and Pat all spoke. The draft CDC school district study follows in its entirety with the exception of the eleven data tables which were eliminated due to space constraints.

INTRODUCTION

The following brief narrative summarizes the descriptive findings of a recent Centers for Disease Control (CDC) and New Jersey State Department of Health field study of the social and economic impact of Lyme disease in school children living in a five-township area of Monmouth and Ocean counties, New Jersey. The analysis of data is restricted to cases (students in grades K-12 in the five-township area who, because of illness diagnosed as Lyme disease, required home instruction in the school years 1990-91 and/or 1991-92). Data on controls are not included because interviews with controls are incomplete. The data provided in this report are derived from interviews with parents of 65 case-patients from 54 households.

The background of the investigation, the methods employed (including a copy of the questionnaire), and preliminary summary statistics are included in a report from Dr. Susan E. Lance to CDC Epidemiology Program Office, with copies to the New Jersey State Department of Health, dated August 4, 1992.

SUMMARY STATISTICS

Age and Sex -- The mean and median age of case-patients was 13 years (range 5-18 years). The range for the two mid-quartiles was 11.5 to 15.5 years. Females comprised 74% of case-patients.

Household Income -- The median household income (grouped by \$20,000 increments) was \$40,000 to \$60,000. Only one case-patient lived in a household having an income of less than \$20,000; 32 (50.8%) case-patients lived in households with incomes of \$60,000 or greater.

Lyme disease in other Family Members -- A total of 43 (66.2%) case-patients lived in households that had at least one other family member who ever had a diagnosis of Lyme disease; 24 (36.9%) cases lived in households having 2 or more other persons who ever had Lyme disease. The mothers of 26 (40%) cases had a diagnosis of Lyme disease, and fathers of 6 cases had a diagnosis of Lyme disease. Cases were more likely to have sisters than brothers with a diagnosis of Lyme disease (43.1% vs 18.5%, respectively).

Characteristics of Illness -- Erythema migrans (EM) rashes with lesions 2 inches or greater in diameter were noted in 7 (10.8%) cases. A tick bite in the month preceding onset of illness was remembered by 17 (26%) patients. Frequent symptoms included severe headache (92.3%), severe fatigue (89.2%), stiffness of the neck (67.7%) and unexplained joint pain (89.2%). Thirty-three (50.8%) case-patients had unexplained joint swelling, and 29 (44.6%) were said to have had physician-diagnosed arthritis. One student (1.5%) had meningitis, and 3 (4.6%) had facial (Bell's) palsy. Eight (12.3%) case-patients were said to have had an abnormal electrocardiogram, and 10 (15.4%) were said to have had physician-diagnosed Lyme disease of the eye. Non-specific symptoms were frequent, e.g., forgetfulness (87.3%), difficulty in concentrating (96.8%), and falling behind in school work (85.7%). Serologic test results were said to be positive in 54 (84.4%) of 64 case-patients.

Clinical Case Definition -- Thirty-one case-patients (47.7%) met a simple clinical definition, as follows: EM 2 inches or greater in diameter; or, physician-diagnosed arthritis, meningitis, Bell's palsy, abnormal electrocardiogram or Lyme disease of the eye, and a positive serologic test for Lyme disease. Thirty-two case-patients (49.2%) did not meet this clinical case definition, and 2 (3.1%) were not able to be completely evaluated. Of the 31 cases meeting the clinical definition, 7 (22.6%) had EM, 3 (9.7%) had facial palsy, and 25 (80.7%) had arthritis with swelling of the joints.

Duration of Illness -- Only 17 (26.2%) cases were thought to have fully recovered from their illness at the time of interview. The mean total duration of illness for all cases was 753 days, the median 363 days, and the range was 9 to 5,110 days. The range of the mid-quartiles was 158 to 960 days. The mean number of

days in which the illness was said to have significantly affected normal activities was 501 days, with a median of 293 days and a mid-quartile range of 112 to 713 days.

Hospital Care -- Fifty-one (78.5%) cases were hospitalized for Lyme disease; 44 (88%) of these cases were hospitalized at Jersey Shore Hospital. Cases were hospitalized for a mean of 35.2 days (median 11 days; range of 2 to 549 days; mid-quartile range of 4 to 28 days).

Treatment -- Sixty (92.3%) patients were treated with intravenous antibiotics, and 63 (96.9%) patients received oral antibiotics. Fifty-eight patients were treated with both intravenous and oral antibiotics; only two patients received oral antibiotics alone. A total of 47 (72.3%) cases received intravenous antibiotics in hospital, and 55 (94.6%) cases received intravenous therapy at home. Forty-two patients (64.6%) received intravenous therapy both in the hospital and at home. The mean duration of intravenous therapy was 118.7 days (median 50 days, range 6-730 days). Forty-three (82.7%) of 52 patients for whom data were available received more than 4 weeks of intravenous antibiotic therapy, and one-half of these 52 cases received more than 8 weeks of intravenous therapy. Thirty patients were thought by parents to have had a relapse after initial antibiotic treatment, 7 were believed not to have gotten better with treatment, and 34 (52.3%) received retreatment at least once.

Complications of Treatment -- Complications of antibiotic treatment were frequent and sometimes severe. One-fourth of the case-patients (24.6%) developed possible hypersensitivity rashes during treatment. Similarly, about one-fourth (23.1%) developed possible drug-induced diarrhea. Some patients were treated with antihistamines and/or corticosteroids to control rash illness, and many patients were given acidophilis supplemental treatment to reduce the occurrence of diarrhea. Eight (13.3) patients who received intravenous antibiotics developed evidence of gall bladder disease during drug treatment, and some were diagnosed as cholecystitis and/or cholelithiasis. Two patients underwent cholecystectomy as a consequence of what was considered to be antibiotic-induced gallbladder disease. Examples of other adverse consequences elicited in non-structured questioning included: venous thrombosis (1), infection at the catheter site (1), sepsis (1), fever (3), hair loss (1), depressed white blood cell count (2), immune suppression requiring bone marrow transplant (1), stomach pains (6), shock (1), yeast infections (1).

Days of School Lost and Requirement for Home

Instruction -- The mean number of school days missed because the case-patient was "too ill to attend" was 103 days (median 47 days, range 2 to 548 days, mid-quartile range 21 to 128 days). The mean number of missed days of school because of intravenous therapy was 84 days (median 40 days, range 4 to 576, mid-quartile range 23 to 96 days). The median number

of total school days lost was 140 days (mid-quartile range of 50 to 219 days). The mean duration of home instruction was 153 days, with a median of 98 days and a range of 5 to 792 days. The range of the mid-quartiles was 30 to 190 days.

Total Direct Medical Costs -- Parents were asked to provide their best estimate of total direct medical costs per case. Estimates were available for 54 case-patients. The mean estimate was \$96,569 (median \$48,076, range \$215 to \$1,000,000, mid-quartile range \$19,000 to \$98,250).

Home Intravenous Medication Costs -- The mean cost of home intravenous antibiotic therapy for 41 patients for whom data were available was estimated to be \$63,323 (median \$19,750, range \$2,000 to \$910,000, mid-quartile range of \$11,000 to \$59,216).

Hospital Costs -- The mean cost of hospital care for 26 cases was \$28,573 (median \$10,000, range \$200 to \$235,250, mid-quartile range \$4,441 to \$22,124).

Physician Costs -- Mean payments to physicians for direct medical care for 33 case-patients were estimated to be \$14,419 (median \$2,660, range of \$150 to \$101,180, mid-quartile range of \$1,475 to \$14,600).

Laboratory Costs -- The mean costs for laboratory services, as provided by parents of 27 case-patients was \$2,775, and the median was about \$2,380.

Oral Medication Costs -- Mean oral medication costs, based on information for 33 case-patients, were \$3,393 (median \$1,850, mid-quartile range \$275 to \$4,004).

Indirect Cost due to Lost Time Caring for Patient -- Parents of only 16 patients (24.6%) provided information on lost income attributable to providing care. The mean cost was \$11,418 (median \$7,120, range \$272 to \$64,000).

Indirect Cost due to Lost Time Visiting Clinics or Hospital-- Parents of 10 patients provided cost data on time lost in transport to and attendance at a physician's office or a hospital. The mean cost was \$3,519 (median \$600, range \$160 to \$18,000).

Social Costs of Illness -- Parents of fifty (78.1%) case-patients stated that their children experienced a fall in grade point average during the time of their illness. Parents were also asked about the impact of illness on their child's extracurricular activities, such as music and dance, sports, summer school or camp, and opportunities for extracurricular learning, including work experiences. It is difficult to quantitate such losses, which were incurred by nearly all case-patients, usually in several categories. Thirty-three of 42 (78.6%) case-patients were said by parents to have experienced a decrease in the number of friends, and 44.2% were said to have had a decrease in the number of contact hours with friends.

DISCUSSION AND CONCLUSIONS

This study is not a detailed analysis of costs of putative Lyme disease in school children in the five-township study area of New Jersey. The results do, however, show the multiplicity and magnitude of the social and economic consequences to students requiring home instruction and to their families. Other studies in-progress document the costs to school districts to provide home instruction.

The distribution of cases by age and sex show a clustering by adolescence and female gender. Although control data are not available, there was a higher prevalence than expected of cases having families with one or more other persons diagnosed as Lyme disease. Mothers of cases were more than four times as likely as fathers to have a diagnosis of Lyme disease, and sisters of cases were nearly two-and-a-half times more likely to carry the diagnosis of Lyme disease than brothers. Families mostly had incomes in the middle and upper-middle class range, and all but one family had at least partial health insurance coverage for the case-patient's illness.

The signs and symptoms at time of onset of illness and later in the course of illness were often atypical of Lyme disease as described in published case series (2, 3). Erythema migrans was reported for only 8 (12%) case-patients; little more than half (36) the case-patients had physician-diagnosed rheumatologic, neurologic or cardiac signs of Lyme disease. Less than one-half of patients met a case definition similar to the one used for national surveillance purposes. Disease in the case-children was remarkably long-standing: only about a quarter of the students were thought to have fully recovered, despite a median duration of illness of 363 days and a median duration of illness with a significant impact on activities of 293 days. Relapses, recrudescences, and incomplete responses commonly prompted repeated courses of treatment. More than 80% of the case-patients were hospitalized, almost exclusively for initiation of treatment with antibiotics at first, and later for incomplete responses, relapses and complications of the treatment. Although the median duration of hospitalization was 11 days, one-quarter of the case-patients were hospitalized for 4 weeks or longer. One child was hospitalized for nearly two years. Nearly all case-patients were treated with at least one course of intravenous antibiotics; some were treated with long continuous schedules, others with repeated shorter courses.

The study documented a high frequency of occurrence and severity of direct adverse effects of antibiotic treatment, including diarrhea and hypersensitivity skin rashes, each occurring in about one-fourth of patients, and more severe consequences such as sepsis and leucopenia. Nearly one in seven patients receiving intravenous antibiotic therapy developed what was thought to be drug-induced gall bladder disease, and two of these patients underwent cholecystectomy for this complication. Crystalline precipitates of drug and bile salts

causing reversible “pseudocholelithiasis” and cholecystitis have been reported in the medical literature as a rare consequence of ceftriaxone use (4, 5). The high frequency of occurrence in this case-patient series may be related to the long courses of ceftriaxone treatment sometimes prescribed.

The schooling of students in this study was severely disrupted. The median duration of school absence was the equivalent of more than one-half of a school year. In many instances, the time lost was broken up, so that disruptions occurred throughout a school year or school years. About the same number of days of absence was attributed to the antibiotic infusion treatment itself as to ill-health. The presence of an in-dwelling catheter and the need for daily infusions was responsible for a median absence from school of nearly 6 weeks, and in one instance for an absence of 576 days. Some students did, however, attend periods of school while on intravenous infusion therapy. The median duration of home instruction was 14 weeks; in 25% of cases instruction extended beyond 27 weeks.

The direct medical costs incurred by case-patients were remarkable. The total costs for 54 cases for whom estimates were available was \$5.2 million. The median cost was nearly \$50,000, and costs of \$100,000 or greater were incurred by more than one-fifth of all patients. The single largest cost was for home intravenous infusion - - the median cost for the 42 patients supplying information was nearly \$20,000. In contrast, the median cost of oral antibiotics for the 33 patients for whom data were available was less than \$2,000. Average costs of hospitalization were about twice that of physician costs. Indirect costs to the families were not easily obtained. Some accommodations by parents preserved income, e.g., work at night or in the home. Persons who stopped work or deferred salaried employment to care for patients were not able to reliably estimate losses directly related to the care. Other indirect costs associated with the case-patient’s illness, such as providing special foods, entertainment, transportation to physician’s offices, etc., were usually overlooked by families as indirect costs of illness.

Perhaps the greatest costs incurred by the case-patients were the social costs of the illness and its treatment. Schooling and extracurricular learning activities were seriously interrupted for most case-patients; often, patients spent large blocks of time as semi-invalids, isolated from social groups and missing out on cultural, sports and social activities. Some parents stated that the case-patients had been ostracized by their peers. School performance of nearly all patients fell, sometimes drastically, and in several instances was said to interfere with selection by colleges and universities. Several patients and their family members required psychologic help to better cope with the illness. One child was hospitalized for depression. Parents often acknowledged that the family had been “consumed” with the illness and its treatment.

There is a compelling need to follow the present study with one that more accurately measures the direct and indirect costs of the broader range of Lyme disease patients in the community, addresses issues of diagnostic and management practices, more fully examines the costs and services of home infusion, and addresses policies of health insurers as they relate to reimbursing claims for the diagnosis and management of Lyme disease. A special study is needed of the frequency of occurrence, severity, prevention and control of adverse consequences of intravenous antibiotics in patients requiring prolonged treatment.

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