

The Economic Costs of Newly Diagnosed Lyme Disease

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<국문초록>

Lyme질환의 경제적 비용분석

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Lyme질환은 미국 코네티컷주의 라임지방에서 관절염증상을 보이는 소아과환자에게서 1975년 처음 발견되었다. 사슴, 노루, 개 등에 기생하는 진드기에 의해 전염되며, 발병초기

에는 감기증상을 수반한 황소의 눈과 비슷한 붉은 반점이 생긴다. 적기에 치료하지 않으면, 관절염, 심장질환, 안면신경마비 등으로 악화될 수 있다.

본 논문의 목적은 두가지로 나누어 볼 수 있다. 먼저, 진단초기의 Lyme질환과 관련된 의료 및 기타 경제적 비용을 저렴하게 계측할 수 있는 방법론을 개발하고 그 유효성을 검증하는 것이다. 둘째로, Lyme질환의 비용에 대한 여러종류의 총괄적 계측치를 제공하고 발병의 위험요인을 색출하는 것이다.

본 논문에서는 차트분석이나 임상연구 등 고가의 비용이 수반되는 분석기법 대신에 Lyme질환 다발지역에 대한 설문조사를 실시하고 그 유효성을 재설문조사를 통해서 검증하는 방법을 사용하였다.

자료분석상의 난점은 조사대상자마다 응답하지 않은 항목(Missing Value)이 다르기 때문에, 총비용을 계산할 때 모든 항목에 응답한 조사대상자만을 사용한다면 표본의 크기가 너무 작아지는 것이었다. 이에 대한 대안으로 총비용 및 부분별 비용의 합을 계산할 때 표본의 일부가 응답하지 않은 항목에 대해서는 그 항목에 응답한 나머지 조사대상자의 응답치 평균을 대체하는 방법을 사용하였다.

통계적 분석결과, 질환의 증상시작부터 설문조사시기까지 Lyme질환과 관련된 사회적 총비용은 US\$ 6400으로 추정되었다. 이중에 200가량은 환자의 보호자와 관련된 비용이고 나머지는 환자와 관련된 것이다. 총의료비용의 평균은 계산방법에 따라서 US\$ 3000~4200의 범위를 보였다. 응답되지 않은 항목을 해당항목에 대한 응답치평균으로 대체하였을 때 총의료비평균은 US\$ 4108이었다. 시간비용은 생산성손실에 대한 사회적 가치와 실제임금 손실의 두가지 방법에 의해 계산되었다. 실제임금손실은 생산손실의 사회적 가치의 약 30%에 불과하였다.

본 논문의 결과는 의료비용 및 비용과 생산성손실에 대한 정보가 지역보건담당자에 의한 전화설문조사에 의해 경제적이고도 일관성 있게 수집될 수 있다는 근거로 해석될 수 있다.

KEY WORDS : LYME DISEASE, ECONOMIC COSTS, SURVEY DESIGN, SOCIAL VALUE

INTRODUCTION

Background

Lyme disease was first identified as a distinct clinical entity in 1975 among pediatric patients presenting with juvenile arthritis in Old Lyme Connecticut. Since then, the causative agent has

been identified to be a spirochete, *Borrelia burgdorferi*. Lyme disease can present initially with erythema chronicum migrans associated with systemic “flu-like” symptoms^{2~3}. Left untreated, some patients go on to develop more severe and debilitating symptoms as : arthritis ; cardiac complications of conduction abnormalities and heart failure ; and a myriad of neurologic manifestations such as Bell’s palsy, radiculitis and possibly memory loss, difficulty concentrating, and confusion^{4~6}.

The presenting symptom in some cases may be that of the arthritic, cardiac or neurologic complications rather than the classic rash. Lyme disease is treatable especially in the early stages of the illness⁷. However, early diagnosis and treatment may be delayed due to the variable presentation and the lack of highly sensitive and specific diagnostic tests for Lyme disease.

There has been ample anecdotal information about disabling nature of the illness which have resulted in loss of time from work or school^{4~6}. Many also report that some of the symptoms associated with Lyme disease which may be difficult to diagnose interfere with daily activity at the premorbid levels^{4,8~9}. There are also recent reports that some patients with late stages of Lyme disease especially chronic arthritis, are refractory to multiple intravenous treatments. The full economic burden of Lyme disease is currently not known.

In New Jersey, the first cluster of Lyme disease was identified among military recruits in Earl Naval Weapon station in Monmouth County in the early 80s. Since then the number of Lyme disease cases reported among New Jersey residents have dramatically increased from about 20 cases in 1981 to over 500 reported cases in 1988. The reasons for the dramatic increase in the number of reported cases may be attributable to heightened awareness of the disease and overdiagnosis¹⁰ but probably more accurately reflects the true disease in New Jersey.

Purpose

- 1) The primary purpose of the study reported here was to develop and test an instrument intended to collect measures of medical care and other economic costs associated with newly diagnosed cases of Lyme disease. The instrument would be administered in telephone interviews by local public health personnel, to persons who had Lyme disease reported to state public health offices.

- 2) From the data in this pilot study, estimates will be generated of the medical care and other economic costs of persons newly diagnosed with Lyme disease.
- 3) Information on other risk factors will be collected for this population.

Importance

The overall objective was to determine whether useful and reliable information on risk factors, medical costs, and economic costs of Lyme disease could be collected with this method. If the method is found to be useful, its relatively low cost may recommend it for other reportable diseases as well. In addition, the information on the medical and economic costs of Lyme disease will itself be valuable, since virtually no non-anecdotal information exists at the present time.

METHODS

Choice of Study Areas and Populations

Monmouth and Ocean counties are areas in New Jersey with high incidences of Lyme disease. Passive surveillance techniques showed that in 1988 and January-April 1989, these counties accounted for 54% and 70%, respectively, of all reported cases in the state. Parts of these two counties were selected for the study because of the high incidence of disease and the interest shown by the local health departments in following reported cases, providing information to health professionals and the public, and improving the reporting of the disease. These health jurisdictions have staff assigned to Lyme disease surveillance and follow-up, and they agreed to participate in the study.

Presently, all cases of Lyme disease presenting to health care providers (hospitals or physicians) are reported to the State Department of Health. Those reported cases that were diagnosed by a physician and/or detected through follow-up of positive serologies constituted the population studied in this project.

Date Collection Techniques

All such patients reported to the local health departments during the months of July and August, 1989, were contacted by telephone by personnel of the local health department, and were given a structured telephone interview.

Each contact occurred approximately 30 days after the date of report.

For the study, all reported diagnosed cases of Lyme disease in the participating health jurisdictions were intended to be interviewed by telephone.

In cases where the patient was a young child, a parent or other responsible adult member of the household was interviewed.

A questionnaire was developed for this study in order to obtain information pertaining to demographic characteristics, clinical illness, risk factors, and costs, and time lost from normal activities associated with the disease and prophylactic measures.¹¹ The participating health departments conducted a pilot field study using cases reported before the period chosen for the study, and the suggestions of the interviewers were taken into consideration for the development of the final survey instrument used.

Validation Techniques

The consistency and reliability of survey responses were checked by a resurvey technique. After the first month of the interview process, 10 percent of the returned surveys for each of the seven interviewers were resurveyed.

Respondents were given an abbreviated questionnaire in a follow-up reinterview. The questionnaire consisted of either the first or second half of the survey instrument. The survey instrument was divided after so that one part of the responses dealt with the risk factor and medical information, while the second half focused predominantly on the medical care use and illness cost information. The degree of consistency in responses was assessed for each part of the resurvey.

Selection of individuals for the reinterview was random. In a very small number of cases, reinterviews were also undertaken when initial responses were judged by the interviewer to evidence confusion about one or two of the questions.

While it would have been desirable to compare the information on medical care use, self-reported estimate of charges, and days missed from normal activities with provider, insurer, or employer and school records, confidentiality requirements and the limited project budget precluded this step.

In future research, however, such validation would be desirable. Nevertheless, there is no reason to suspect that answers, though they may be subject to error, will be biased.

Statistical Analysis

Information on risk factors, medical care charges and insurance payments, and economic costs was summarized. The primary objective of the data analysis was to calculate mean values and standard deviations of total economic cost and its components.

Total economic cost is defined here as the sum of direct medical costs, other direct costs associated with the illness, and the cost of time lost due to illness from other activities, for both patient and caregiver.

Means were also estimated for various subsets of patients—defined by age, sex, and time elapsed between the onset of symptoms and measurement of cost. Significance tests for differences in means were implemented, and descriptive multiple regressions with cost measures as dependent variables and various patient characteristics as explanatory variables was estimated.

Missing data items were estimated when there was sufficient information to do so. The sensitivity of results to such imputation techniques was determined.

When expenditure data was missing but the respondent indicated that services had been received, we estimated the missing data items. In such cases, we substituted the average expenditure for those who reported positive expenditures for the missing item in each category. For example, for persons who reported that they received inpatient hospital care but did not report total expenditures, we substituted average inpatient expenditure per respondent who reported the amount of expenditure.

Measures of Cost

We provide several aggregated measures of cost. For the cost of medical care, we add up the physician/clinic, drug, hospital, and other medical costs. We also provide a regression analysis in which total medical cost is related to duration of disease, and insurance coverage and other patient characteristics.

The other component of cost is represented by the value of lost output for patient or caregiver due to the disease. For patients or caregivers who are employed, we use measures directly related to the person's wages. The most direct measure is the amount of pay the patient or caregiver lost because of time spent seeking care, providing care, or because of the need to stay in bed.

The Public Health Service cost of illness methodology would, however, generally regard actual pay lost as an underestimate of the true economic cost for an employed person.¹² Even if the person does not lose wages—because of sick leave benefits or because the employer permits employees to take off from work to see a doctor, the output the person would have produced is still lost : there is a cost to someone. Accordingly, we provide another measure pricing out sick time and time spent seeking care at the hourly wage rate. Where the individual did not report an hourly wage, we divide total family income by an estimate of hours worked to get a wage rate.(This may lead to an overestimate, since it assumes that the individual's wages make up the great bulk of family income.)

For individuals who are not employed, the PHS methodology imputes a wage rate to those who report their occupation as “housewife” or “homemaker.”(This set is almost entirely females.) We have also followed that convention, using the wage rate in New Jersey for domestic services as the proxy.

Finally, we note that some respondents reported their occupation as “retired.” Since at least some of these respondents may also have been providing household services(a retired female clerical worker might be more likely to list employment as “retired”, and a retired male who lives along almost surely produces domestic services for his(one person, household), we provide an alternative calculation in which we price time at the wage rate for domestic services for individuals who are not students and not employed.

RESULTS

Measures and Methods

The minimum time required for an interview was approximately 20 minutes ; many interviews required more time due to the duration of the illness, the number of treatments obtained by the patient, and/or the interest of the respondent. There were a number of reported severe cases of long duration that had either been previously undiagnosed as Lyme disease and treated as if the symptoms were due to another illness, or had been unresponsive to earlier medical treatment for Lyme disease ; in these cases the patients often seemed interested in helping future victims from being subjected to the same frustrations they felt.

The response rate was very high for both the initial and the follow-up(consistency checking) interviews. All reported cases were contacted, and no person contacted refused to give an interview. A total of 165 interviews were administered. Usable information was obtained from 160 of them, for a response rate of 97 percent.

<TABLE 1> SURVEY RESPONSE RATES, OVERALL AND BY
SELECTED INTERVIEW ITEMS

Toal Number of Patients Contacted for Interviews	165
Number of Interviews Completed	160
Response Rate by Interview Items(Denominator = 160)	
	%
Respondent identification	98.8
Complaint identification	95.6
Complaint that prompted initial visit	26.3
Location of tick bite(if known)	75.0
Occupation	
Onset year	95.6
Insurance deductible	63.8
Number of physician/clinic visits	92.5
Physician/clinic visit charges	86.9
Hospital inpatient charges	85.0
Days in bed	95.6
Care by others	86.3
Patient time missed from work or school	75.6
Family income	91.9
Total Medical Cost	51.3
Inpatient Charges	31.9
Wage Rates	62.5

A few respondents refused to question pertaining to the wage rate or socioeconomic status of the patient or family. All other questions were answered if the respondent knew the answer.

In a somewhat larger number of cases, respondents did not know the answer to particular questions. <Table 1> shows the "maximum feasible" number of respondents who were eligible

to provide answers to each question, and the number who actually did so. For most questions, the maximum feasible number of respondents is the sample size of 160. For some questions, however, the number is expected to be smaller. For example, only employed persons were able to answer questions about work time and wage rates.

As indicated in the table, the largest number of missing individual answers occurred in connection with questions about total charges. This was especially true for inpatient care.

The second highest frequency of nonresponse was reported for the wage rate and income measures. To some extent, this probably reflects the fact that the respondent was not always the person whose wage rate and income were being queried. This is almost always true for the questions that ask about time provided by other caregivers, and can be true for the patient himself or herself. The nonresponse rate was not judged to be sufficiently severe that resort to estimation of missing values was warranted.

One question was ambiguous about whether the wage rate to be reported was that of the patient, rather than the respondent. For those cases in which the respondent was the patient, or in which the patient had already been reported as not employed, no ambiguity arises, nor does it arise where no wage rate is given. Twenty-six out of 165 interviews recorded a wage rate when the respondent was not the patient but the patient was employed. In the data to be presented, we substituted in such cases an estimated wage rate based on family income and an estimate of the number of work hours per family. However, in any further use of this instrument the wording should be changed.

Another question that might, in retrospect, be ambiguous is one which asks about days in bed due to illness. It was not clear from the wording whether these "days" were to include or exclude the hospital days queried earlier.

Quantitative Findings

Descriptive Statistics. <Tables 2 to 5> describe both respondents and patient characteristics. Of the 160 subjects responding, about half (81) provided answers themselves. A parent was the next most common respondent. The average age of patients was 32 years. Forty-one percent were male. As indicated in Table 3, 44 percent were under 18, and 15 percent were over 65.

<TABLE 2> PATIENT AND RESPONDENT CHARACTERISTICS

N=165

Proportion Respondents Patient	51
Proportion Respondents Parent of Minor Child	37
Proportion Respondents Spouse of Relative	12
Proportion Respondents male	41
Mean age	32
Standard Deviation of Age	23

<TABLE 3> AGE DISTRIBUTION OF PATIENTS

Unknown	6.1
0–6	10.9
7–18	26.7
19–35	17.5
36–50	17.0
51–64	6.1
65+	15.2

<TABLE 4> OCCUPATIONAL DISTRIBUTION OF PATIENTS

Frequency (%)

Student	32
Retired	25
Housewife	16
Professional	10
Office Work	8
Services	7
Child	32
Other	27
No Response	8

The most common occupations, described in <Table 4>, were student, housewife, retired, and professional. More than 80 percent of respondents reported spending less than 5 hours per week outdoors at work.

The great majority of respondents, as shown in <Table 5>, were covered by either of two types of private insurance. Medicaid/public assistance and Medicare covered a small percentage. Family income was about \$ 34,658 on average in 1989 dollars. For those who worked and reported an hourly wage rate, the average was \$ 15.90 per hour.

<TABLE 5> DESCRIPTIVE STATISTICS AWARENESS OF AND CARE SEEKING FOR LYME DISEASE

	%
Source of Information about Lyme Disease	
Print Media	37.4
TV	12.3
Physician	10.3
Friend	10.3
Other and no response	29.7
Prior Knowledge of Lyme Disease—Yes	86.0
Location of Tick Bite	
Home	20.6
Farm	1.8
Camp	1.8
Other known site	3.0
Unknown	72.8
Insurance Coverage of Patient	
Blue Cross/Blue Shield	30.9
Commercial Insurance	32.7
HMO	6.7
Medicare	15.2
Other, no insurance, no response or unknwn	14.5

<TABLE 5> DESCRIPTIVE STATISTICS
TIMING OF SYMPTOMS AND TREATMENT
(continued from previous page)

Year	Onset of Symptoms	First Medical Contact	Diagnosis
79~86	8.5	6.1	2.4
87	4.2	3.6	1.8
88	17.6	17.0	9.7
89	65.5	69.7	83.0
Unknown/No Response	4.2	3.6	3.0

The most frequently reported area in which the tick bite occurred (Table 5), was home (21 percent). However, only about a quarter of the respondents could describe where the bite occurred (and less than half (42 percent) recalled a tick bite at all). The great majority (86 percent) of respondents knew about Lyme disease beforehand, with print media (37 percent) by far the most common source of knowledge.

<Table 6> shows the complaints that prompted the initial physician visit. The most common complaint was a rash (44 percent of respondents), followed by swollen joints (28 percent), and fatigue (17 percent). The most common symptoms that first occurred after the problem began were fatigue (88%), and swollen or painful joints (70%). Finally, respondents most commonly received a diagnosis of arthritis (28 percent) and erythema chronicum migrans (17 percent), when a specific additional diagnosis was provided by a physician, as shown in <Table 7>.

<TABLE 6> COMPLAINT THAT PROMPTED INITIAL VISIT FOR CONDITION
THAT TURNED OUT TO BE LYME DISEASE

	Frequency (%)
Red Rash	44
Swollen Joints	28
Fatigue	17
Headache	15
Fever	12
Other Complaints	42
No response	7

<TABLE 7> PHYSICIAN-DIAGNOSED CONDITIONS

	# Yes	# Valid Responses
Bells Palsy	9	160
Meningitis	2	158
EKG Changes	13	157
Arthritis	45	159
Erythema Chronicum Migrans	27	158

<TABLE 8> MEAN REPORTED USE AND TOTAL EXPENDITURES FOR
CONDITION THAT TURNED OUT TO BE LYME DISEASE,
TIME OF ONSET TO TIME OF SURVEY
(NUMBER RESPONDING IN PARENTHESES)

	Mean Values Complete Responses Only	Standard Deviation	Estimated Means, Missing Values Estimated (Visit Data Sample)
Clinic or Doctor Office Visits	7.4 (157)	10.6	7.4 (157)
Office Visits Cost	\$ 515 (139)	1000	515 (157)
Outpatient Medication Cost	\$ 610 (139)	2091	670 (157)
Other Outpatient Medical Expenses cost(Tests, Home Health)	\$ 928 (142)	3790	947 (157)
Number of Respondents Reporting Inpatient Use	51		
Days Inpatient	2.98 (160)	5.87	2.98 (160)
Inpatient Charges	\$1268 (136)	3708	1976 (159)
Total Medical Costs, Respondents Answering All Components Only	\$ 3215 (82)	6891	
Estimated Total Medical Costs All Respondents	4108 (157)		

Medical Care Costs. <Table 8> shows average medical care costs for various components of medical costs and for total medical care costs in 1989 dollars. While the response rate for each of the components is reasonably good, the combination of missing data elements in the four components of total cost considerably reduced the number of responses with valid values for all components. The last line of the table shows the results of attributing the average expenditure of respondents who did report actual expenditure to those respondents who reported use of some services but did not report the dollar amount. Respondents who failed to answer concerning use were deleted.

Mean total medical care costs are in the range of \$3000 to \$4000, with the largest component of average cost represented by inpatient care. Positive values of inpatient expense were reported by 28 respondents and ranged from \$250 to \$23,000 with four respondents reporting expenses in excess of \$10,000.

The next highest component is other outpatient medical expenses, including tests, home health care, or “other outpatient expenses.” The average expense of \$928 for other outpatient expenses was associated with high total expenses for a minority of patients. As <Table 9> shows, 10 patients reported expenses in this category of more than \$2,000. The table also shows that almost all of these patients had high expenses in other categories, suggesting that the answers do reflect a valid pattern of consistently high expenses by individuals with what are presumably severe conditions. The same pattern is shown in <Table 9> for outpatient drug expenses with 12 patients (out of 114 giving valid answers) reporting drug expenses in excess of \$2,000—and high expenses in other categories.

<TABLE 9>

	Number With		Number with
	Total Inpatient Expense		MD Cost > \$200
Total Expense, Drugs > \$2,000	12	10	11
Total Expense, Other > \$2,000	0	8	9

We also examined the mean values for various subgroups in <Table 10>. There was a difference in average total expenditure by gender, with males showing a somewhat lower cost than females. However, the large standard errors mean that no differences in this table are statistically significant at the usual levels. The fifth column shows average expenses for those whose condition began in 1989. As might be expected, their average expense is not as large as the average expense over all patients.

<TABLE 10>

	Age < 32	Age > 32	Males	Females	Year of First Medical Care in 1989
Mean Office Visits Cost	436	599	209	714	258
N	(72)	(67)	(52)	(83)	(99)
Standard Deviation	848	1142	239	1243	643
Mean Medication Cost	869		675	938	319
N	(163)		(47)	(63)	(83)
Standard Deviation	2311	1801	2119	2136	1104
Other Outpatient Cost	1208	586	788	1086	764
N	(78)	(64)	(58)	(79)	(102)
Standard Deviation	4673	2288	2842	4469	3987
Inpatient Cost	1784	705	635	1499	829
N	(71)	(65)	(54)	(78)	(101)
Standard Deviation	4153	3084	3231	3363	2759
Total Medical Costs	3745	2100	1977	3528	1859
N	(82)	(76)	(62)	(91)	(115)
Standard Deviation	7513	5626	6488	6669	5895

We further estimated a multiple regression with total medical expense as the dependent variable, and age, sex, and time of onset as explanatory variables. No regression coefficient was significant, and the F test for regression as a whole did not meet the 0.05 significance criterion. Given the high variation in expenditure (the standard deviation around the mean is almost three times the mean), this sample is not large enough to detect differences in means across population subgroups.

<Table 11> shows the mean value of other outlays associated with Lyme disease. On average, these costs are minor.

Lost Time and Time Cost. Time can be lost due to Lyme disease in two ways. People may take time away from work, school, housework, or leisure in order to receive medical care, and they may also stay in bed or be unable to perform normal activities because of the illness. The true economic cost of the time lost from work in either case is the wage that would have been paid, since the wage should proxy the value of the individual's work time. Because of sick leave provisions and workplace practices, the person frequently will not lose pay to the same extent. We measured actual lost pay for outpatient medical visits, and found it to be about 30 percent of the estimated value of time. In the results that follow, however, we measure the social value of lost work time by the wage rate, regardless of the amount of actual pay lost.

<TABLE 11> MEAN REPORTED EXPENSE FOR OTHER EXPENSES AND TOTAL COST OF ILLNESS FOR CONDITION THAT TURNED OUT TO BE LYME DISEASE (NUMBER RESPONDING IN PARENTHESES)

	Comple Responses Only
Special Clothing Cost	\$ 7 (151)
Repellents Cost	12 (151)
Other Precautions Cost	19 (150)
Other Non-Medical Costs (Remodeling, Equipment)	13 (153)
Pet Treatment Cost	10 (153)

<TABLE 12> TIME COST OF LYME DISEASE
(NUMBER RESPONDING IN PARENTHESES)

		Proportion Greater Than Zero
Patient time off from work/school for office or clinic visit(hours)	23.9 (144)	.31
Actual lost wages for visits	\$ 130 (132)	—
Value of lost work/school time, visits, employed persons	# 435 (116)	—
Value of lost work/school time, visits, all persons	\$ 315 (160)	—
Others' time off from work/school for visit(hours)	6.8 (153)	.28
Value of others' time off for visits(at \$ 10.00 per hour)	\$ 68 (153)	—
Patient days in hospital	3.0 (160)	.32
Illness days in bed	17.8 (158)	.47
Days missed from work/school	16.7 (126)	.33
Days others missed from work/school	1.7 (154)	.19
Value of others' days missed	\$ 97 (154)	—
Value of work days missed(workers only)	\$ 2458 (100)	—
Value of housewife illness time(days in bed only)	\$ 344 (15)	—
Value of retiree illness time(days in bed only)	\$ 921 (25)	—
Average value of lost time, all respondents (= value of days missed for worker and housewife illness time and retiree illness time) (workers and housewives and retirees and children)	\$ 1712 (160)	—

For housewives and retired persons, no money wage is paid. The convention in cost-of-illness studies is to price housewife time at the wage rate of domestic workers. We have followed that convention here, pricing out an hour of housewife time at the New Jersey average wage rate for domestic workers. We count days in bed, at home or in the hospital, at the average wage per day (8-hour workday, 5 workdays per week).

Time retired people spend in bed is typically not counted as part of the cost of illness. There apparently are no retired housewives, though a female over 65 might have listed occupation as “retired” or “housewife.” Retired males may also provide some household services, even though they would not list occupation as “housewife” or “domestic worker.” We therefore provide a calculation that prices out retired persons’ time in the same way as was done for housewives.

Finally, we also calculate the cost of time spent by friends or family members assisting the person in outpatient visits or caring for the person in bed.

<Table 12> displays the average values in 1989 dollars. Employed persons lose \$ 435 in time for doctor or clinic visits, and the average value for all persons is \$ 315. The average value of time lost from work due to illness was \$ 2458 per worker. The value of time in bed for housewives was \$ 344 per housewife. Retirees’ time valued at the domestic wage rate has a cost of \$ 921 per retiree. Adding to time in bed an estimate of the value of time spent in the hospital would raise these estimates by approximately \$ 350 per worker and \$ 125 per housewife or retiree ; we have not done so in the calculations which follow. We calculated average value of lost patient time due to illness for all patients by summing the value of lost work time, housewife bed days, and retiree bed days, and dividing by the total number of patients responding(160). The average value of lost time per patient(including children, whose value is set at zero) is \$ 712.

DISCUSSION

Total Costs and Their Interpretation

<Table 13> summarizes the various cost components and provides an estimate of the average total social cost of Lyme Disease from onset of symptoms to interview for the patients in

our study. Because of missing data items, the sample size for those patients who gave valid responses for each and every data item would be small. We therefore show total cost calculated by adding the average values for each of the cost components. In these calculations, the hours provided by others were valued at \$10.00 per hour.

<TABLE 13> TOTAL ECONOMIC COST OF LYME DISEASE
(SUMMARY)

Mean Medical Cost = \$ 4108
Mean Other Expenses = \$ 61
Lost Time of Lost Work Time Due to Illness = \$ 1712
Mean Value of Lost Work Time Due to Illness = \$ 1712
Total Cost for Patient = \$ 6196
Time Cost for Others, Visits (at \$ 10.00 per hour) = \$ 68
Time Cost for Others, Caring for Patient = \$ 97

Total Social Cost = \$ 6361

Under this method of calculation, the total social cost of illness for this set of patients, from onset of symptoms to the time of the interview, was approximately \$6400 per patient. Of this cost, about \$200 is borne by caregivers. There is, of course, substantial variation about the total social cost. A few patients, primarily those who were hospitalized, had very high costs. Most patients incur lower cost; indeed more than half of all patients had total cost (medical plus time) of less than \$500. Nevertheless, it is clear that the average total cost of Lyme disease per patient is a substantial amount. Were Lyme disease to be prevented, this data provides an estimate of part of the cost saved per case prevented.

Feasibility of Data Collection

This project provides convincing evidence that information on medical care use, cost, and time lost from normal activities can be gathered in an economical and consistent fashion by means of

follow-up telephone interviews administered by local public health personnel. While external validation of some of the cost and use measures will be desirable, it is clear that much of the information on time lost from normal activities and time provided by others can only be gathered in this way.

With the exception of only a few items, the survey instrument seemed capable of being administered easily. Respondents were able to understand the questions, and no unusual difficulties were encountered. Again with only a few exceptions, answers could be interpreted unambiguously and clearly.

Interpretation of Results

While this survey was administered in only a few sites, the estimates of symptoms, use of care, and cost all seem plausible. It should be noted, however, that this technique provides a lower bound estimate to the total cost of Lyme disease, since some patients may well have incurred cost after the interview period. The persons surveyed could be thought of as including three types of patients. One type was diagnosed correctly at approximately the time of onset of symptoms and was treated with no recurrence of symptoms. For this “cured” group, the data presents an accurate estimate of total costs. Another group of patients were diagnosed correctly, but their condition continues to need care at the end of the observation period ; for these “uncured” persons, costs up to the point of the survey will understate total costs. Finally, there are those whose symptoms appeared much earlier, who were not diagnosed or not reported promptly, and whose care continues. This group’s costs are probably underestimated somewhat.

There are two other groups whose costs are not measured in the survey. Those who were diagnosed and reported earlier, but are still receiving care during the period of observation, are not included in the sample. Neither are those for whom first symptoms occurred during the observation period, who are receiving care for those symptoms, but who have not yet been diagnosed or reported.

Finally, the costs incurred to rule out Lyme disease for persons who are suspected of having the disease but who are not diagnosed as having it are not taken into account. These costs would

be avoided if Lyme disease was eradicated in the insect host.

A useful strategy would be one in which, in addition to the items already included, respondents were asked about their current symptom or stage of disease(insofar as the latter can be elicited in an interview). This information would permit selected follow-up of those who report that active symptoms or sequellae continue at the interview period.

Conclusion

Lyme disease is a condition which is costly to treat. It causes a non-negligible loss of productivity, and imposes costs on others. Even though these estimates do not include the costs of care obtained by people who suspect that their symptoms are Lyme disease, even though they do not turn out to be so, the estimates suggest substantial gain if the disease can be prevented.

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