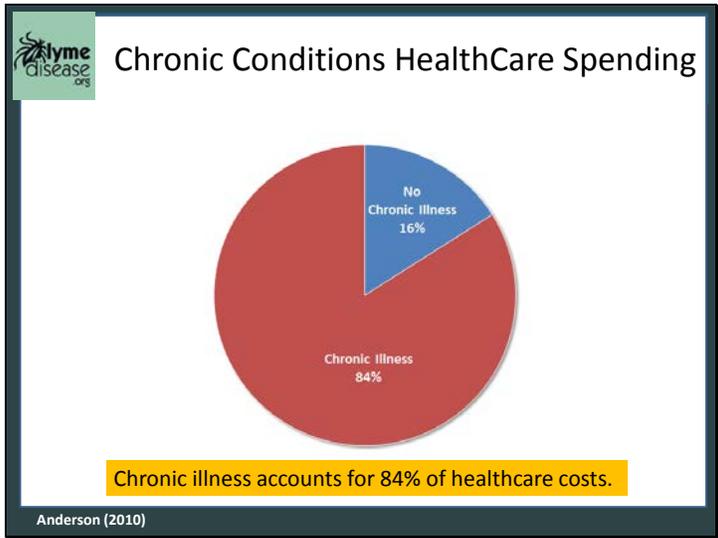
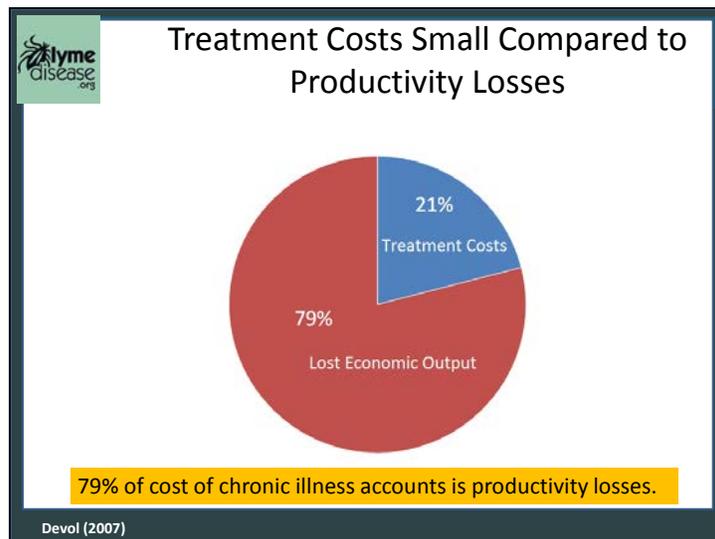


This chart book discusses the cost of chronic illness generally, the costs associated with Lyme disease in particular, and—most importantly—the extent to which those costs have been displaced by insurers onto patients, their families, communities and, ultimately the government as patients denied longer term care by their insurers shift from full time to part time employment, become unable to work full time, or are forced to seek state or federal disability. A number of studies are highlighted, but this chartbook primarily focuses on results from large scale surveys conducted by LymeDisease.org and the findings of a study by Dr. Zhang of the CDC published in 2006. Dr. Zhang’s study is the most extensive cost of illness study conducted in Lyme disease. LymeDisease.org conducts and publishes in peer reviewed medical and healthcare policy journals robust surveys of patients with Lyme disease, typically drawing responses from over 4,000 patients.

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Before turning to Lyme disease, it’s important to understand the cost of chronic illnesses generally. Most of us are aware of the problem of mushrooming health care costs. What you may not know is that most of the increased cost growth in health care is associated with chronic conditions. In fact, 84% of the costs of health care spending in the United States is related to chronic conditions. The costs increase each year as more people enter the pool of those with chronic conditions. The costs here reflect only medical costs. They do not reflect loss of productivity and the impact on quality of life due to chronic illness. (Devol 2007)

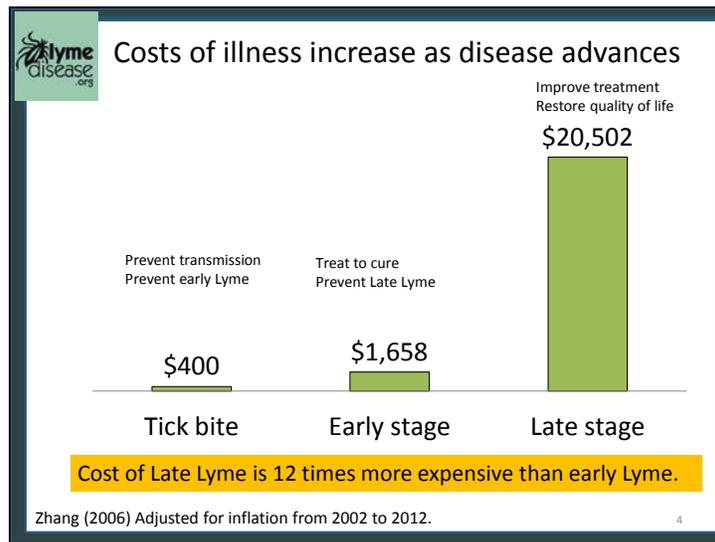


However, medical costs are just one component of the total costs of illness. There are four primary components of the cost of an illness:

- direct medical costs borne by the insurer,
- indirect medical costs borne by the patient such as co-payments,
- non-medical cost like those incurred for a caretaker in the home,
- and loss of productivity costs, which principally relate to lost wages.

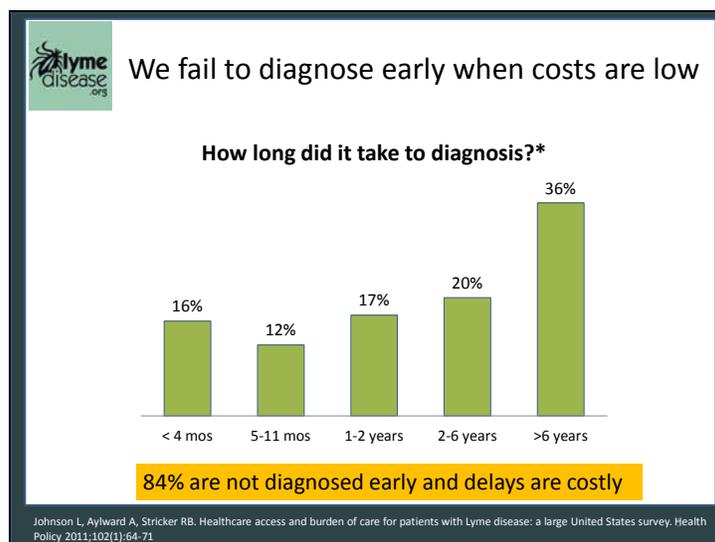
It is estimated that 79% of the cost of all chronic illness is from lost economic output of employees and only 21% of the cost is attributable to treatment costs. (Anderson 2010) This means that to reduce the total costs of the illness, we are going to get more bang for our buck—relatively speaking—by reducing loss of productivity than by reducing medical costs because that is where most of the cost is.

Insurers are only responsible for direct medical costs. Indirect medical costs like copays and the cost of loss of productivity and nonmedical costs are borne by the patient, the family, the community and ultimately the government through lost revenues from income taxes when people can't work, through a lower gross domestic product, and through disability support payments paid by governments to those disabled by a disease. It is easy to cut medical costs, but if we increase loss of productivity in the process—then we're simply shifting the burden of the disease from insurers to society—and we may actually increase the total costs as will be discussed later.

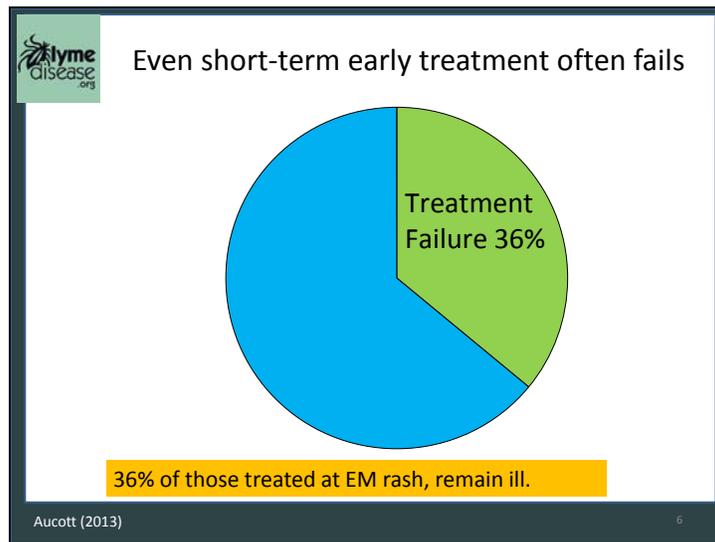


Keeping these points in mind, let's turn to the cost of illness in Lyme disease. These figures are taken from the CDC study by Dr. Zhang of the total cost of illness associated with Lyme disease and include an adjustment for inflation from 2002 to 2012. (Zhang 2006) What you should notice in this chart is that the cost of Lyme disease goes up exponentially over time. If we treat Lyme effectively at tick bite, the cost is quite modest. If we wait until early Lyme disease, the cost has risen to \$1,600—that's provided we treat it effectively at that point. If the person goes on to develop late Lyme or chronic Lyme, the costs skyrocket and we are looking at over \$20,000 per person in costs annually. It's pretty clear looking at this chart, what we need to do to control all costs in Lyme disease: We need to prevent transmission and aggressively treat the bite; we need to diagnose early Lyme promptly and treat to cure; and we need to aggressively treat late Lyme disease to restore people to their productive lives—to get them back to work, back in the community, off disability. Right now, we are failing on all three of these goals.

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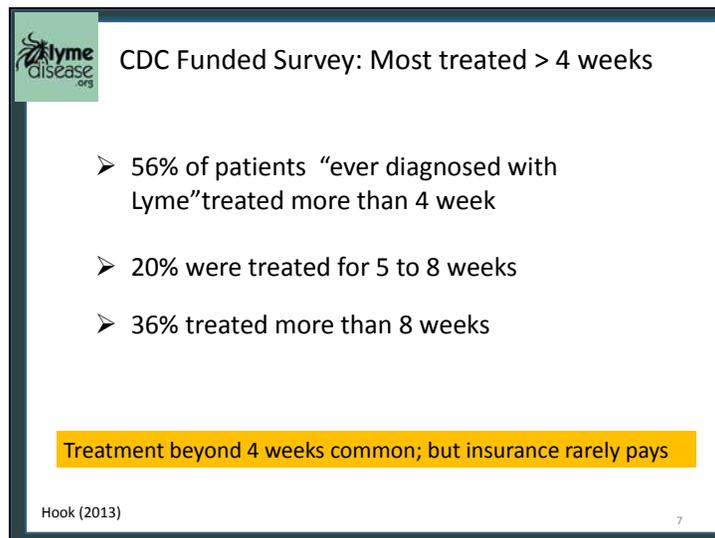


For example, we are not diagnosing Lyme early, when it is more easily treatable and the costs are low. In our surveys of patients with chronic Lyme—late diagnosis was a major factor in their development of chronic Lyme disease. 84% were not diagnosed early. (Johnson 2011)

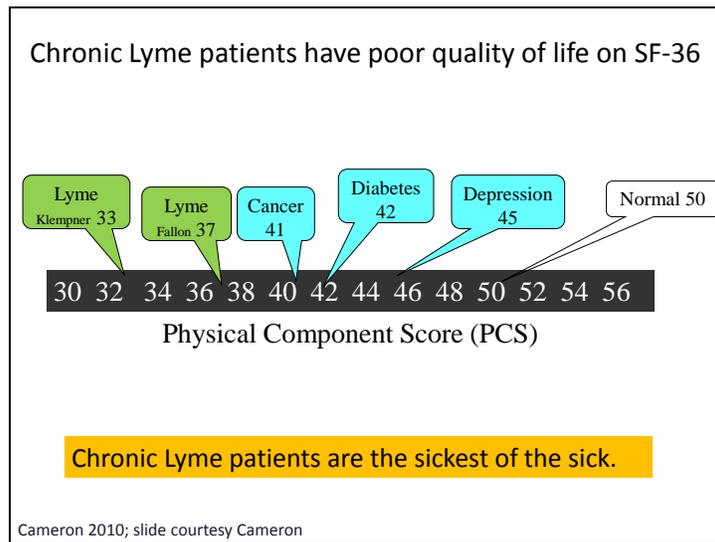


What about those who are diagnosed early? A study by Dr. Aucott at Johns Hopkins found that 36% of those who are diagnosed at EM rash remain ill six months after treatment. (Aucott 2013) So we aren't doing enough to aggressively beat this disease when it is beatable. And a lot of physicians know this.

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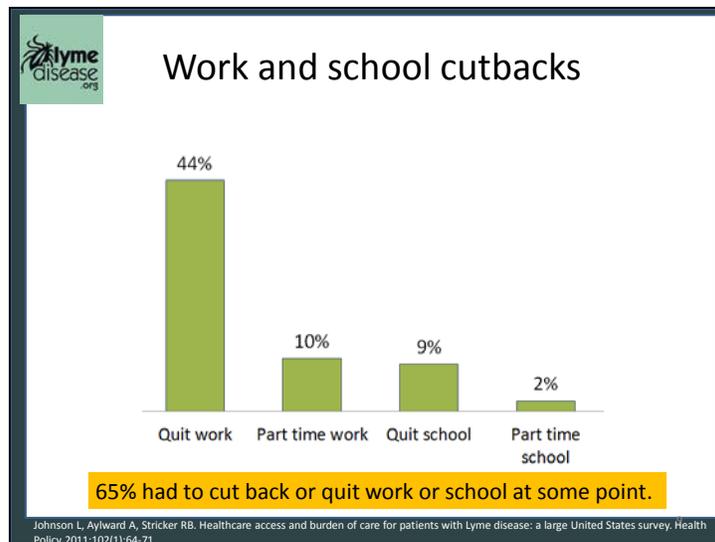


A CDC funded study by Dr. Hook and colleagues which is in the process of being analyzed and published found that the majority of patients were being treated for more than 4 weeks and 36% were being treated for more than 8 weeks. (Hook 2013) What this tells us is that short term protocols are not working—even for early disease. The failure rates are too high. So we need to aggressively treat this disease when it is the easiest to treat. And we won't get there with insurance guidelines that limit treatment to 4 weeks.

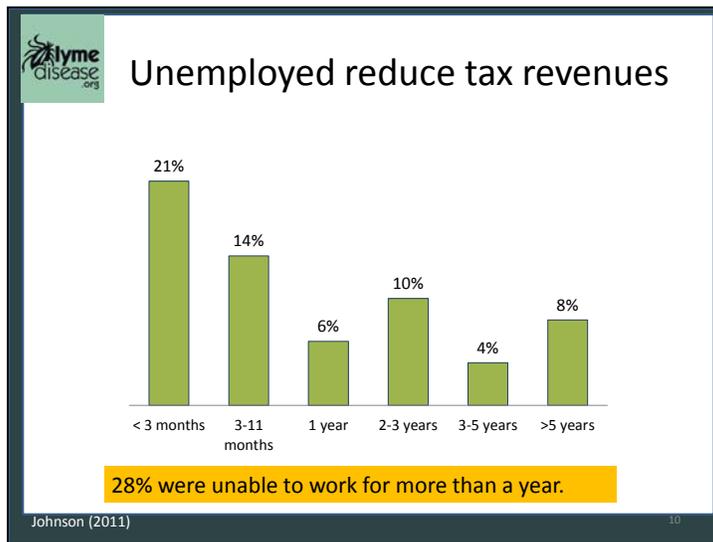


What about chronic Lyme? Why is it so important to treat early Lyme effectively? This figure is a comparison of chronic Lyme with other chronic illnesses, using the physical component of the SF-36 scale, which measures Quality of Life. (Cameron 2010) What this figure tells us is that the physical burden of chronic Lyme exceeds that of cancer, diabetes and depression. It's a long, long way from normal. Essentially, chronic Lyme patients are the sickest of the sick. And, this is reflected in their ability to work and whether they are forced to go on public disability.

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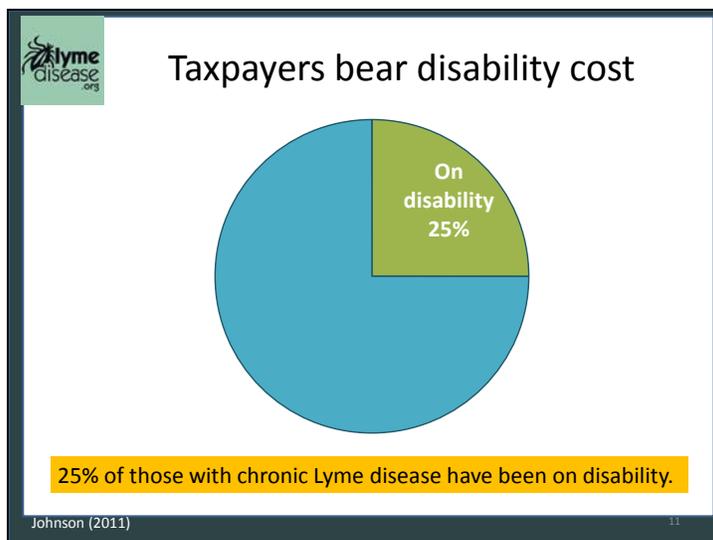
Our survey of over 4,000 patients with chronic Lyme found that 65% of patients had had to cut back on work or school at some point in their illness. 44% had to quit work and another 10% had to shift from full time to part time work. Another 9% had to quit school altogether and 2% had to cut back to part time school. (Johnson 2011)



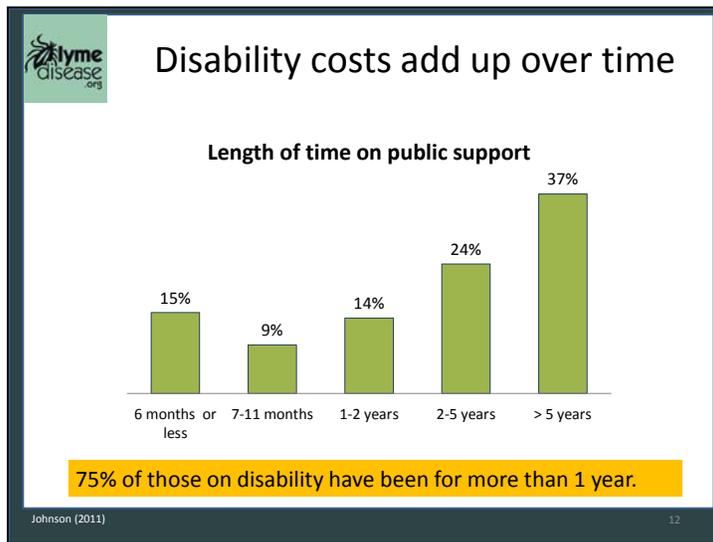
How long people were unable to work or go to school varied, but for 28%, it was for more than a year, for 22% it was for 2 years or more, and for 8% it was for more than 5 years. (Johnson 2011) Bear in mind, this question was not about cutting back from full time to part time, but dropping out of the work force or school altogether.

These people are not only unable to work and support their families, they also exact a societal cost through reduced gross domestic product and taxable income resources. Unfortunately, many are ultimately forced to go on disability support.

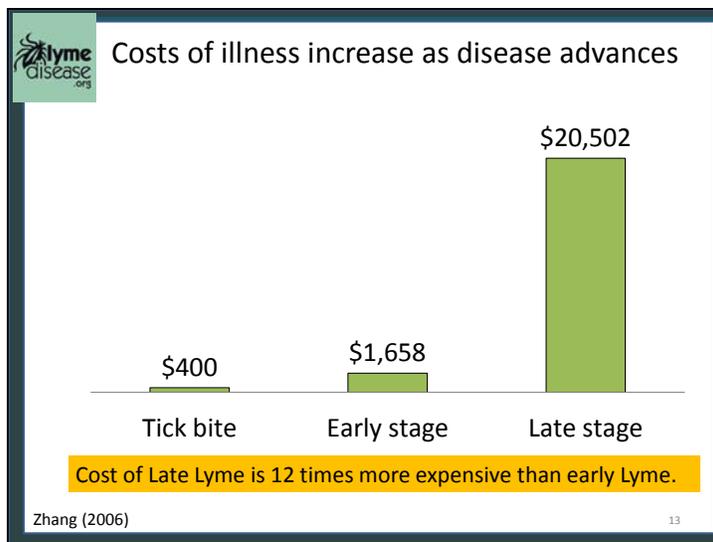
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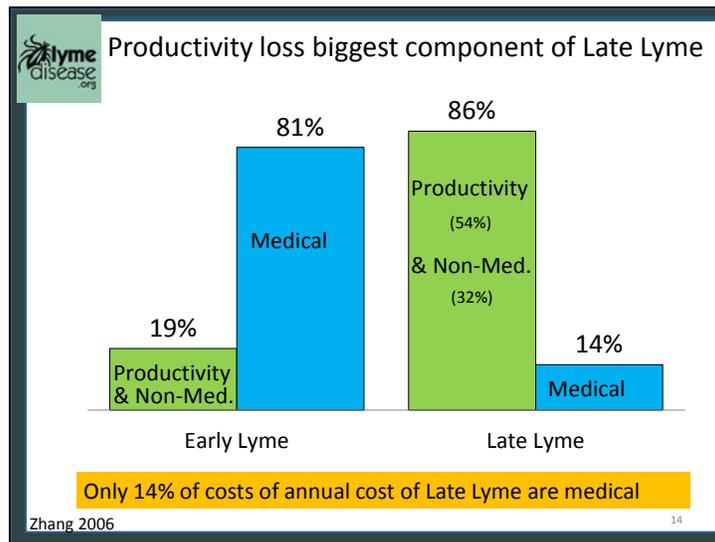
In fact, one of our published studies found that 25% of patients with chronic Lyme had been on public support at some point. (Johnson 2011)



Of those who have received disability at some point, 75% had been on disability for more than a year and 37% had been on disability for more than 5 years. (Johnson 2011) That’s a huge drain on public resources, and it’s a cost we can’t afford to ignore.

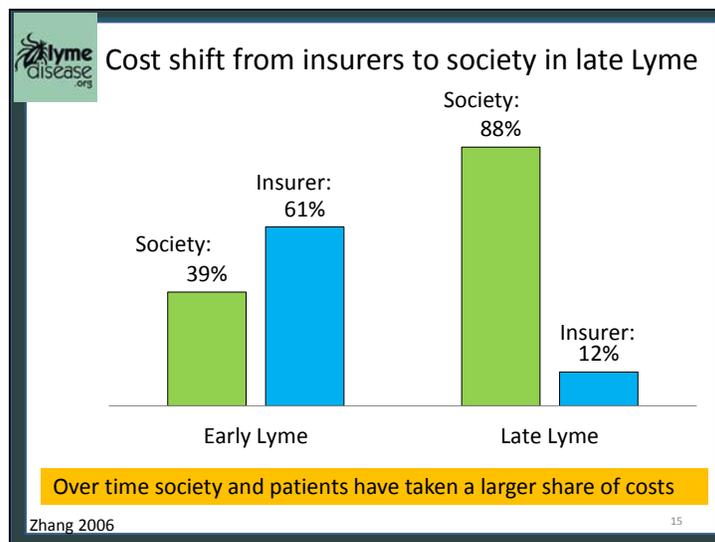


Let’s go back to Zhang’s break down of costs for Lyme disease. It is important to bear in mind the fact that the \$20,000 cost of illness in late Lyme is an annual cost—that is it goes on for as long as these people are ill. And mainly it goes on as long as they are unable to work or are disabled because most of this cost is loss of productivity.

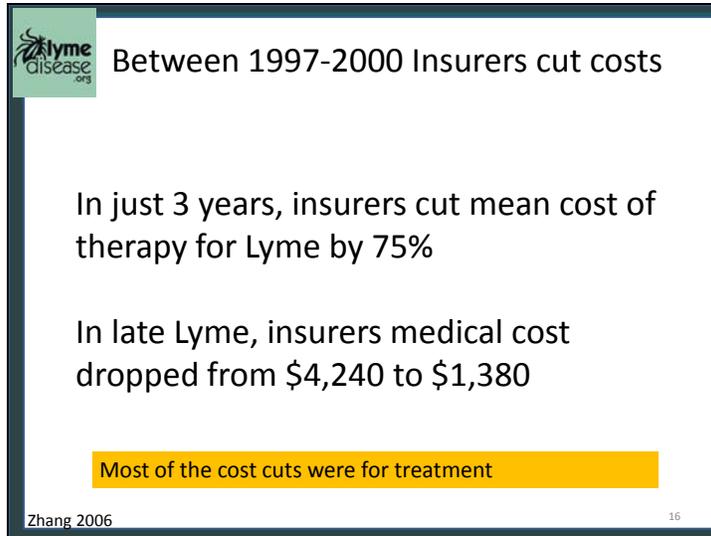


One of the key things Zhang tells us is that the percentage of medical cost for early Lyme is quite high, while those for late Lyme are quite low. As you can see in this chart, the medical costs in Late Lyme are only 14% of the total costs. 86% of the costs are either loss of productivity—folks who can't work—or non-medical costs, like caretakers. Not only are the costs of early Lyme small (\$1,600) compared to the annual costs of Late Lyme (\$20,000), but in early Lyme almost all of the cost is medical costs. Here's another way of looking at it, in early Lyme the insurers bear almost all of the cost, but in Late Lyme almost all of the cost is borne by patients, families, communities, and, ultimately, government. [Note, medical costs on this chart include both direct medical costs, borne by the insurer, and indirect medical costs such as co-pays, borne by the patient.]

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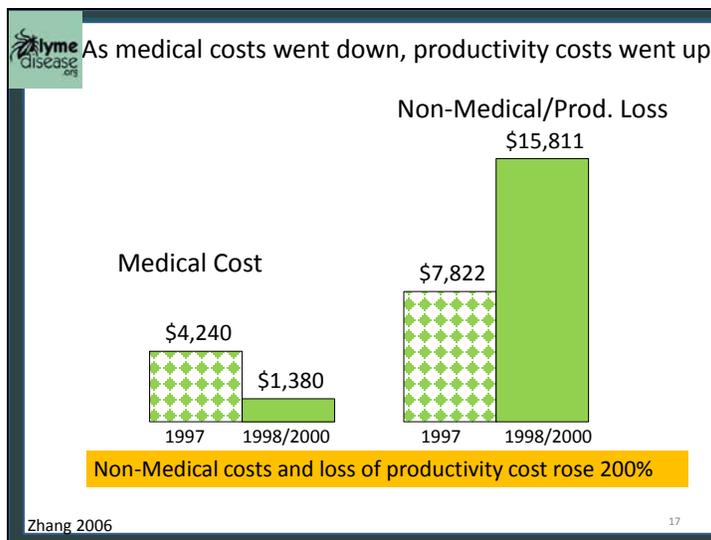


In fact, when you look at this from the vantage point of simply who pays—or who bears the burden, the cost shifting from insurers to society becomes apparent. Indirect medical costs, the non-medical costs and the loss of productivity are all borne by the individual or society. In contrast, insurers only bear the direct medical cost—which in late Lyme, Zhang tells us, represent just 12% of the total costs. [Note, insurer costs on this chart exclude indirect medical costs such as co-pays, which are borne by the patient.]



Zhang’s study suggests two reasons why insurers bear so little of the cost of Late Lyme and patients and society bear so much. The first reason is that during the period of his study insurers cut treatment costs for all stages of Lyme disease by 75%. The second reason is that loss of productivity and non-medical costs for late Lyme rose enormously during this same period.

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More specifically, medical costs (primarily for treatment) for late Lyme were reduced from \$4,240 to \$1,380. But these costs cuts were more than offset by a 200% increase in non-medical costs and loss of productivity costs. These costs increased from roughly \$8,000 to \$16,000. The result is that the total costs of disease went up, but the proportion of the expenses borne by insurers went down.

**Medical costs cut, total costs increased**

**Cost of Late Lyme**

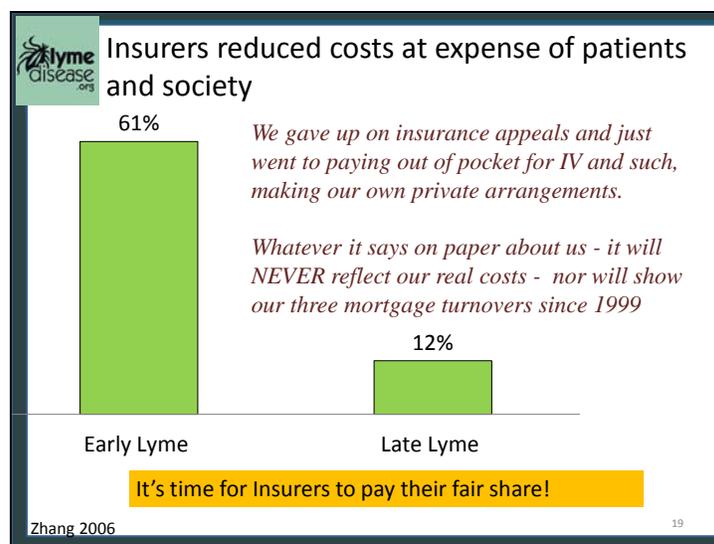
	1997	1998/2000
Direct Medical	\$4,240 ↓	\$1,380
Indirect Medical	\$579 ↓	\$389
Non-Medical	\$60 ↑	\$6,703
Loss of Productivity	\$7,762 ↑	\$9,108
<b>Total</b>	<b>\$12,641</b>	<b>\$17,580</b>

Medical costs down; non-medical costs & productivity losses up.

Zhang 2006 18

This table shows the whole story--how insurers cut medical costs in late Lyme, but increased the total cost of illness by increasing productivity losses and non-medical costs, like caretaker support.

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While insurers pay 61% of the costs of early Lyme, they pay only 12% of the costs of late Lyme. Denials of coverage are widely reported by patients with late Lyme and even those with early Lyme who require treatment beyond 4 weeks. Patients, of course, can appeal these denials, but, the fact is, they rarely win. In states where independent medical reviews have been evaluated, less than 10% of patient appeals succeed (compared to 50% or more for other conditions).

The question is what do we do now that the displacement of costs from insurers to patients, their families and the community is clear? It's easy to cut medical costs—all you have to do is deny care. But if denying care means more people become unemployed or are forced to go on disability, then that is a trade-off that works well for insurers but harms the public. From our surveys, we know that patients with Lyme are denied care all too frequently and that antibiotics improve the quality of life for most patients. We believe it's time to ask the insurers to start paying their fair share and that this bill is a step in the right direction.



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### About LymeDisease.org

LymeDisease.org is a non-profit corporation that is a central voice for Lyme patients across the nation through advocacy, education and research. LymeDisease.org maintains state-based advocacy groups throughout the nation and emphasizes evidence-based medicine and healthcare policy. Its executive director sits on the patient engagement panel of the Patient Centered Outcomes Research Institute, a federal research funding organization founded by Congress. She is also the Co-Chair of the Steering Committee for Consumers United for Evidence Based Healthcare, a coalition of over 40 patient advocacy organizations, which seeks to define the role of the patient in evidence-based medicine.

LymeDisease.org seeks to increase patient participation in all aspects of healthcare policy-making by promoting meaningful direct involvement in research grant selection and guideline development. It advocates for legislation to protect physicians who treat Lyme patients and to secure healthcare coverage for patients. It educates patients, physicians, and policymakers through the internet, social media, and our quarterly journal, *The Lyme Times*. It informs the medical community and policymakers through medical journal publication and our community physician training grants. In addition to funding research, it conducts and publishes in peer reviewed journals robust (4,000 plus respondents) surveys of those with Lyme. For more information visit [lymedisease.org](http://lymedisease.org).

