



Lyme Disease—the Public Dimension

Health lobbying and greater public engagement in science, now amplified by the Internet, carry both merits and demerits

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During a recent talk, I mentioned the increasing number of reports in medical journals about people who have harmed themselves by following health advice, and sometimes buying weird nostrums, from the Internet. Recent cases include a man who developed severe nephropathy after consuming a Chinese herb “to enhance his liver” and another whose online purchase of prednisolone for a self-diagnosed illness triggered the development of bilateral cataracts and glaucoma.

“But those examples are not typical,” said someone in the audience. “You are overlooking the enormous amount of authoritative guidance and real help now available on the net. People are learning about rare syndromes and new therapies, bringing important information to the attention of their doctors and securing earlier, more appropriate treatment, as well as saving time and money. All of this is revolutionizing medical care. There are bound to be a few difficulties, but they are totally outweighed by the benefits.”

My critic had a point. Yet I remain concerned about the huge quantity of nonsense that now flows through the global electronic highway, and its practical consequences. This is certainly an area ripe for a dedicated piece of research. Notwithstanding some real gains, I suspect that a systematic study of health advice available through the uniquely powerful, unregulated Internet would reveal far more disquieting examples than beneficent ones.

Meanwhile, we can learn from specific case histories about the impact of the Internet on medical research and practice. An especially telling example is Lyme disease. The story of this condition, since it hit the headlines just over 30 years ago, is instructive because it vividly illus-

trates both the positive importance, and the drawbacks, of greater public involvement in the advancement of medical science and health care. On the one hand, concerned citizens rather than medical experts first highlighted the full significance of Lyme disease. On the other hand, public clamor, much of it centered around the Internet, has now derailed the introduction of a highly effective vaccine against the infection.

The story began in 1975, when a vigilant mother in Connecticut noticed that 12 children in the village of Old Lyme (population, 5,000) had developed an illness that had been diagnosed as juvenile rheumatoid arthritis. Local doctors appeared unconcerned. So the woman, increasingly perplexed and worried, reported the matter to her state health department. Around the same time, another villager independently telephoned the Rheumatology Clinic at Yale University to describe an “epidemic of arthritis” in her family. This pattern, too, had not been picked up by the otherwise meticulous health surveillance machinery of the state of Connecticut.

At first, officials were deeply sceptical about the claims from Old Lyme, and impatient with the villagers’ demands that the mystery be investigated. Who had ever heard of arthritis appearing as an epidemic? Arthritis was not an infectious disease—it was a degenerative condition associated with ageing. There was simply no way in which it could spread around a community like chickenpox or measles.

Fortunately, researchers at Yale did take the women seriously and began to monitor what was happening. By 1977, they were convinced that there was indeed an outbreak of arthritis around Old Lyme. As well as aching joints and a stiff neck, the disease caused a headache and fever. Two other striking characteristics were



that it tended to begin in the summer, and appeared among children or adults several weeks after an unusual sort of spot had suddenly developed on the skin.

The first real clue to the mystery came when one patient recalled having been bitten by a tick at the site of the spot. Investigators discovered that a particular type of tick, usually carried by deer, was the carrier of an organism that might cause the disease. Further detective work led to the isolation of a characteristic spirochete from the tick and the demonstration that there were antibodies against it in the blood of Lyme arthritis patients. Finally, Willy Burgdorfer and colleagues described the organism, isolated from patients' blood and now called *Borrelia burgdorferi*, in the *New England Journal of Medicine* (308:216, 1983).

So far, so good. Activists had helped to focus professional attention on a condition that was in danger of being overlooked. But then, in the years following, a bandwagon began to roll as campaigning efforts attracted tens of millions of research dollars annually. Lobbyists portrayed Lyme disease as a national plague, and wielded considerable influence on the research agenda. For microbiologists who believed the condition was little more than a nuisance in certain geographically restricted areas, and who emphasized that it was treatable with antibiotics, the threat was being grossly exaggerated. Just as regrettable was the distortion of scientific research by demands from activists.

"These lay pressure groups are interfering with research. . . . There is science and there is nonscience, and nonscience doesn't belong at a scientific meeting," said Durland Fish of New York Medical College in Valhalla. He was speaking as a member of the programme committee for a conference on Lyme borreliosis held in Arlington, Va., in 1992. Fish's irritation followed the reinstatement of several papers originally rejected by the committee as not being of the requisite standard. Written by nonacademic clinicians, the papers were put back on the agenda largely as a result of pressure from patient-support groups. Principal issues at stake included the question of whether patients described in the controversial reports were really suffering from Lyme disease, which was being

overdiagnosed, and whether they were receiving valid therapies.

One might imagine that the development of a recombinant Lyme vaccine, and its approval by the FDA in 1998, would have been wholly welcome by the campaigners and would have ended their by-now-overheated campaigning. What happened instead, however, was that the activists who had urged the development of a vaccine greeted its arrival with hostility. As described by Lise Nigrovic and Kimberly Thompson of the Children's Hospital Boston and Harvard University, Boston, Mass. (*Epidemiol. Infect.* 135:1, 2007), their angry response, linked with adverse media coverage, fears of side-effects, and declining sales, led the manufacturer to withdraw the product.

According to Edward McSweegan, program officer for Lyme disease research at the National Institute of Allergy and Infectious Diseases in the early 1990s, licensing of the vaccine confronted campaigners with the problem of "how to sustain public anxiety (and donations), media attention, and political clout against the evidence-based reality of a bacterial infection that was antibiotic-responsive, nonfatal, noncommunicable, geographically focused, and preventable through vaccination."

The activists' answer was to target the vaccine's imperfect efficacy, projected cost, and potential booster requirements. "Ad hominem attacks on individuals involved in the vaccine trials quickly followed, stoked by simmering animosity between many patient activists and clinicians over the appropriate diagnosis and treatment of Lyme disease. These personal attacks—and anecdotal stories about Lyme disease in general and the vaccine in particular—took place on the Internet."

Campaigners' websites also purveyed "misleading information about the vaccine, personal 'vaccine victims' stories, and newsgroup bulletin boards offering a repetitive stream of misinformation, libel, and quack treatments." McSweegan argues that, because this was barely answered by researchers, vaccine manufacturers, or public health officials, "the public opinion battles. . . were fought, and lost, in cyberspace."

I fervently hope that lessons have been learned on all sides from this initially positive but eventually dismal story.