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## MALADIE DE LYME : LE REGARD DES SCIENCES SOCIALES

### LYME DISEASE: INSIGHT FROM SOCIAL SCIENCES

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## Résumé

Cet article propose une revue de littérature sélective des travaux de sciences sociales consacrés à la maladie de Lyme, en mobilisant également d'autres travaux menés sur des risques sanitaires similaires. Ces travaux montrent que la borréliose de Lyme constitue un exemple « archétypal » des risques infectieux contemporains. C'est tout d'abord un risque « invisible », dont l'émergence résulte des interactions entre activités humaines, écosystèmes et pathogènes, et pour lequel les autorités de santé privilégient la prévention individuelle. Ce choix implique de mieux connaître les perceptions profanes : distinctes de celles des experts, ces perceptions sont socialement différenciées, sujettes au « biais d'optimisme » et influencées par les récits personnels. De plus, il ne faut pas oublier les dilemmes auxquels sont confrontés les profanes qui envisagent une conduite préventive. Enfin, la controverse sur le « Lyme chronique » illustre bien le désenchantement contemporain à l'égard de la science, le nivellement des positions relatives de l'expert et du profane, et l'immixtion progressive du second sur le terrain du premier.

## **Abstract**

This article is a selective literature review of social science works published on Lyme disease, that draws on other articles published on similar health hazards. These works present Lyme borreliosis as an “archetypal” example of modern infectious risks. It is an “invisible” risk resulting from interactions between human activities, ecosystems, and pathogens. To tackle this risk, health authorities promote individual-based prevention measures. Perceptions of the general population should thus be better understood: different from the perceptions of experts, the general population’s perceptions are socially differentiated, inclined to an “optimism bias”, and influenced by personal stories. One should also not forget the dilemmas faced by the general population when contemplating preventive behavior. The “chronic Lyme disease” controversy illustrates the modern disappointment in science, the leveling of the general population’s and experts’ relative opinions, and the progressive interference of the former with expert matters.

## 1. Introduction

Lyme disease may now be viewed as a unique nosological entity. Transmitted by *Borrelia burgdorferi* following an infected tick bite, the infection is usually considered benign and curable with a few weeks of antibiotic therapy. The annual incidence of Lyme disease is around tens of thousands of cases in France, with great regional disparities. Little attention was paid to this infection in France, either in the research field or in the media, until the end of the years 2000. However, Lyme disease is now the object of scientific controversies and heated public debates. Patients' associations condemn the attitudes of health authorities and physicians, whom they believe refuse to acknowledge and treat a chronic presentation of the disease that they claim to be highly debilitating. Health authorities regret the tension and acrimony of patients' associations, and their "resentment against the medical profession and experts" [1]. The French High Council for Public Health (French acronym HCSP) published a first short report on Lyme disease in 2010, where no mention of these heated debates was made [2]. Another longer report was published in 2014, with a whole chapter dedicated to patients and associations [1].

This article reviews human and social science works on Lyme disease. Our aim was twofold: on the one hand, we aimed to demonstrate how Lyme disease and the associated perceptions, reactions, and debates illustrate several events characteristic of modern societies: when considering this point of view, Lyme disease is not an abnormality but rather an excellent example of new health hazards – particularly infectious – faced by modern societies; on the other hand, by putting Lyme disease into perspective with other health hazards, we hope to demonstrate how human and social sciences help better understand the various perceptions of and reactions to Lyme disease.

We will first see that Lyme disease is an emerging risk, boosted by human activities and thus “manufactured” to some extent, and an invisible risk or at least only accessible via scientific tools. This emerging and invisible nature of risk results in chronic and endogenous health crises. As health policies are increasingly based on individual-based preventive behaviors, one should focus on understanding the general population’s understanding of risks: studies performed on Lyme disease-associated perceptions remind us of a few major results on risk perceptions. We will finally contextualize the controversy on the chronic presentation of Lyme disease at a time of modern disappointment in science.

## **2. Emerging risks and health crises: Lyme borreliosis, an archetypal case**

### *2.1. A “manufactured” risk?*

Anthony Giddens and Ulrich Beck, two major sociologists of the end of the 20<sup>th</sup> century, believed modern societies to be threatened by new risks. These new risks are no longer natural disasters but “manufactured” threats, i.e. generated by technologies and human activities [3,4]. One may of course think about the nuclear risk, the various sources of pollution, and the mad cow disease crisis. The latter was highlighted by Beck as it is also an example of people’s disappointment in science.

However, this observation should be nuanced and updated in light of the past few decades. New infectious risks, caused by preexisting pathogens that were previously unknown or poorly known, have indeed emerged because of human activities (legionellosis bacterium, Lyme disease bacterium, Ebola virus, HIV) [5]. The mad cow disease is an example of these new risks, as the incriminated prion has not been created by men but disseminated following transformations of the bovine industry in Great Britain [6]. As for Lyme disease, the loss of agricultural lands and the suburban reforestation – in the Ile-de-France region and in New

England, United States, for instance – led to the proliferation of deer and rodents, acting as reservoirs for *Borrelia burgdorferi* and feeding the ticks by infecting them. Population settlement near forests and the growing taste of city-dwellers for outdoor activities in this environment, have considerably increased human exposure to tick bites [1,5,7].

Merrill Singer's anthropology of infectious diseases describes how this new ecology of human activities, combined with climate changes, resulted in a new epidemiology of vector-borne diseases in Northern countries. This was brought about by the modified hosts/parasites and pathogen/pathogen (coinfections) interactions, and affects differently the various social groups. Patients presenting with Lyme disease in the United States are, for instance, more likely to belong to the upper middle class living in the suburb and to present with a coinfection (Lyme disease and babesiosis) [8]. Merrill Singer thus reminds us that humans both contribute to and suffer from environmental changes.

## *2.2. An invisible risk, that can only be unveiled by science*

Beck believes new risks of the modern world to be remarkable as they are invisible: whether it is microorganisms or radiations, these imperceptible risks can only be understood with scientific tools, and yet often indirectly [4]. Besides contributing to their proliferation, the invisible nature of these risks also contributes to the volatility and diversity of risk perceptions, even more so as science – the only tool able to detect them – is weakened and contested.

Lyme disease is a great example of an invisible risk, as the serological diagnosis consists in detecting in the patient's serum the presence of specific antibodies produced by the organism to fight against the infection caused by *Borrelia burgdorferi*. Yet, part of the controversy between patients and physicians focuses on the diagnostic approach as the bacterium may be present without the antibodies (especially at the early stage of the infection) and conversely,

antibodies may persist after the bacterium disappearance (knowing that some also say that the other diagnostic methods – culture or gene amplification – are not optimal [1]).

### *2.3. An endogenous and chronic health “crisis”*

The common-sense definition of a health crisis involves a major sudden threat with great impact on our daily lives. However, this general conception is not in agreement with the analysis of modern crises [9]. Modern crises do not necessarily take a heavy toll on human lives (e.g., mad cow disease crisis or avian flu virus or H1N1 virus). Similarly, when considering the less controverted acute presentation of Lyme disease, the infection annual incidence is modest (<30,000 cases) and is not supposed to be fatal.

Considering the relative absence of victims, the outbreak of a crisis usually comes from the media coverage of a controversy or from scientific uncertainty. Such controversies or uncertainties are usually pointed out by health authorities (e.g., the mad cow disease crisis was triggered by British authorities themselves in March 1996) or by associations acting as whistle-blowers (e.g., impact of electromagnetic waves on health). Increased health surveillance and media coverage of controversies tend to “chronicize” crises, which thus stand the test of time. For instance, the early warning phase of the H1N1 crisis in France lasted for almost a year, from April 2009 to January 2010. Although the urgency factor is still characteristic of a crisis, crises are increasingly becoming endogenous: no longer triggered by a sudden massive external event, but by social stakeholders [10].

For instance, patients’ associations obviously played a crucial role in the media coverage of Lyme disease [1]. Conversely, this media coverage was also endogenous as it was delayed and structured by organizational factors. The surveillance of health hazards caused by vector-borne diseases in France has long been focused on diseases transmitted by mosquitoes coming from warm countries, at the cost of diseases transmitted by other vectors in the

Northern Hemisphere. Different institutional and scientific authorities were thus responsible for defining recommendations to tackle the issue, with specific perspectives, methods, and measures [11]. For Lyme disease, the focus has first been put on the infectious risk (targeted at the bacterium, diagnosis, and care) and then on the disease vector (reservoirs, interactions between ecosystems and lifestyles). Both of these priorities have long ignored each other. Conversely, for the chikungunya epidemic observed in Reunion in 2005, priority was given to fighting the disease vector, i.e. the *Aedes* mosquito [12]. Drawing on another field, the 2003 heat wave crisis was declared too late by health authorities, which had reviewed their priorities the year before and decided to exclude climate changes [13].

#### *2.4. Preventive actions involving the general population*

Programs aimed to tackle a specific health hazard often entail the general population to follow recommendations issued by the authorities, e.g. by urgently complying with a mass vaccination campaign [9]. In line with the modern risk culture asking everyone to take themselves in hand and to take responsibility of their own health, these measures often focus on individual-based preventive behaviors that need to be promoted via information and awareness campaigns [14].

Lyme disease prevention programs, in France and elsewhere, are in line with this principle as they focus on individual-based preventive behaviors (wearing clothes with long sleeves, using insect repellent, staying on the main forest paths, looking for ticks on one's skin, etc.) rather than environmental changes (treating deer, building fences, etc.) [15,16].

In the United States this desire to increase people's autonomy related to preventive measures is also illustrated by some pharmaceutical companies who tried to commercialize a vaccine against Lyme disease at the end of the 1990s. As Lyme disease is considered a benign disease restricted to specific geographical areas and as infected people cannot transmit the disease

(no herd immunity), this vaccine was not presented as a public health requirement but as an “à la carte” optional vaccine left to the individual’s choice based on the need for control and protection [17].

### **3. Perceptions of the general population**

#### *3.1. Pluralist perceptions, different from the perceptions of experts*

To involve the general population in the fight against Lyme borreliosis, one should first understand how the general population perceives the risk associated with this disease. The general population’s perceptions of Lyme disease are heterogeneous: levels of perception and associated factors depend on the context, for instance on whether or not interviewed people live in an endemic or emergent region for Lyme disease [18,19]. However, despite disparities, constant factors of risk perception analysis are observed in studies focusing on the “Lyme disease risk”. These constant factors had already been observed in various fields – more than 40 years ago for some –, at the crossroads of economics and psychology: i.e., the general population and experts do not have the same perception of a given risk [19,20]; risks are more acutely perceived by women or people with low socioeconomic level [19,21-24]; the risk perceived for oneself is almost always lower than that perceived for others (i.e., “optimism bias” [19,25]).

How do the general population’s perceptions differ from experts’ perceptions? The psychometric paradigm indicates that the general population does not think about a risk just in terms of probability and severity. They also take into consideration other factors: whether it is viewed as manageable at the individual level; whether the risk exposure is perceived as voluntary or involuntary, fair or unfair; whether consequences are immediate or delayed, frightening or insignificant; whether the risk is perceived as familiar or mysterious; whether

the risk is based on established scientific knowledge or on controverted scientific knowledge [26]. Some of these factors are mentioned in studies on the risk perception of Lyme disease [19]. This risk is associated with several characteristics that may startle the general population: still largely unknown by the general public, Lyme disease is associated with a multitude of troubling symptoms, including atypical neurological disorders [1], and it can be perceived as particularly unfair and out of control as it now mainly affects children (at least in France and in the United States) [1,27].

### *3.2. Perception biases: personal stories*

Studies conducted on risk perceptions at the crossroads of economics and psychology reported on perception biases very early on. They mainly reported that a given piece of information does not have the same impact on risk perception depending on how it is presented (i.e., can it be acted upon?; is it striking or spectacular?) [28]. With the development of the Internet, this type of bias is now particularly well illustrated by the multiplication of and access to personal stories. The general population highly enjoys this type of information sources, at the detriment of more “objective” pieces of information disseminated by health authorities. The same holds for vaccination: websites supporting a critical standpoint on vaccines give priority to this type of testimonials [29].

Similarly, a qualitative survey performed in Connecticut, United States, reported the greater trust of people in the experiences of close relatives who contracted Lyme disease than in information disseminated by health professionals and health authorities [30]. A recent study reported that this type of stories was particularly searched for on the Internet [31]. The authors assessed a random sample of 700 videos on Lyme disease (out of more than 150,000 videos on YouTube), with a total of approximately 13 million views. Ninety-two per cent of these videos had been uploaded by private individuals, and almost two-thirds related personal

stories. Analyses revealed that, compared with a video posted by a governmental agency on epidemiological data and prevention advice, a video featuring celebrities talking about their personal experience with Lyme disease will be viewed 18 more times and will be twice more likely to be “liked” by viewers.

### *3.3. Dilemmas and competing risk perceptions*

Studies conducted on risk perceptions revealed that informing the general population is not enough for them to “adequately” perceive a threat and to effectively follow preventive advice: for Lyme disease, several studies highlighted that people with very good knowledge of the disease do not necessarily follow the recommendations [32,33].

This seeming inertia is better understood if we consider what prevention experts often forget, namely that recommendations drafted by health professionals or health authorities leave individuals facing dilemmas [14]. Preventive behaviors may indeed be problematic because they disrupt our daily life, prevent the fulfillment of some objectives, break certain values, or just because they are themselves viewed as risky by people. For instance, vaccination refusal may result from philosophical or religious beliefs, or may be based on fear of potential adverse effects [34,35].

A recent study on Lyme disease reminded that the determinants related to preventive behaviors imply that people believe that the benefits of such approach overcomes its disadvantages [32]. Thus, the most frequently followed precaution measure is checking one’s skin following exposure and by contrast, the least followed measure is spraying acaricides in gardens or lands, probably because of their toxicity [18,36,37]. Similarly, people practicing outdoor activities in forests are reluctant to preventive measures during such activities because they fear that it might impair the associated enjoyment (for instance, protecting oneself by wearing ample clothes when the weather is hot) [38,39].

#### **4. Disappointment in science and controversies: “Chronic Lyme disease”**

##### *4.1. A controversial chronic presentation*

Within months or years following a tick bite, some patients report a variety of symptoms, often highly subjective and poorly specific to the physician’s opinion (myalgia, cognitive symptoms, asthenia, etc.). Some patients, but also some physicians, are convinced to have a chronic presentation of Lyme disease, even though the serological tests (or any other diagnostic methods) cannot confirm the disease. These patients and physicians thus believe that these tests are highly imperfect. These patients are asking for long-term antibiotic treatments, that may sometimes be effective – at least temporarily. However, even though this effectiveness reinforces these people’s conviction, it does not have any diagnostic value because the treatment may target another disease or disorder (even more so as ticks carry many bacteria, viruses, and parasites).

For most physicians and health authorities, this chronic presentation of Lyme disease does not exist. It is considered a “catch-all disease” for people presenting with unexplained symptoms, and antibiotic prescription would not be justified: it would lead to unnecessary costs to society, while antibiotic consumption contributes to antibiotic resistance and could be harmful for patients [1,40]. However, patients believe that physicians do not listen to them, do not understand their pain, and refuse to treat them, even though their symptoms greatly impact their daily life – sometimes leading to loss of employment. These patients gathered together and created patients’ associations in the years 2000 in France and 30 years earlier in the United States. They advocate for the recognition of “chronic Lyme disease” and are highly active on the Internet and social media.

##### *4.2. Disappointment in science and controversies*

The “chronic Lyme disease” presentation also divides physicians and experts, resulting in a major media and scientific controversy [1,11,17]. In the United States the controversy mainly opposes a learned society known as the Infectious Diseases Society of America (IDSA) to a physicians’ association known as the International Lyme and Associated Diseases Society (ILADS). The debate around “chronic Lyme disease” is the perfect example of the disappointment in modern science, which was highlighted by Ulrich Beck [4]. Both the general population and the scientific community are disappointed in modern science as it generates a multitude of highly specialized, fragmented, temporary, and often contradictory results, especially in the biomedical field [41]. Science can no longer decide between contradictory opinions or invalidate biases, quite the opposite: every opinion can be supported by scientific arguments found among the excessive amount of scientific data. This “balkanization of knowledge” is reinforced by new information and communication technologies. They contribute to the proliferation of controversies and to further weakening experts’ knowledge, resulting in the general population’s mistrust in experts’ knowledge [42].

Indeed, every modern controversy now has its “own” experts. During the mad cow disease crisis, some experts questioned the responsibility of the mad cow prion in the transmission to humans while others foresaw hundreds of thousands of victims in the near future. Similarly, what many experts called the “H1N1 flu pandemic” was actually just a minor flu [9].

#### *4.3. Controversies discussing science*

Although disappointment in science feeds controversies, the latter provide the opportunity to confront competing conceptions of science. Each side reproaching the other to lack scientific ground. For instance, two American physicians published an article on the “chronic Lyme disease” controversy. They considered that supporters of a chronic presentation and their “pseudo-science” have declared war to scientific culture and evidence-based medicine. To

better invalidate the opinions of supporters of a chronic presentation, the authors referred to another previous controversy: i.e., the relation between vaccination and autism, which was proven as a scientific fraud [43]. Similarly, the HCSP mentioned in its 2014 report that associations advocating for the recognition of “chronic Lyme disease” are trying “to undermine the legitimacy of professional expert assessment” and have an “anti-science” stance similar to those against vaccination [1]. As for the associations, they frown upon the contempt, denial, and ignorance of Lyme disease that they believe the HCSP experts display [44].

Debates on vaccination, for instance, often present as a defense of science and its principles, especially on the social media: advocates of vaccination try to depict their detractors as an “anti-vaccination” cult associated with an “anti-science” stance. Detractors of vaccination, on the other hand, point to the dogmatism and lack of critical mind of vaccination advocates and highlight the need to enhance technical skills and independence of judgment [45].

The upsurge of the general population and patients in the scientific field is far from new. The general population has long learned how to imitate experts to be able to promote their cause. They collect their own data and perform their own analyses to alert public authorities: this is what the American sociologist, Phil Brown, calls “popular epidemiology”. This term was first coined in the 1980s to describe the investigation work performed by residents living next to a contaminated site to study the prevalence of pediatric leukemia cases near this site [46].

Not only does the general population mimic epidemiology, but they are also trying to change the scientific rules. In the 1990s for instance, associations of HIV-infected patients fiercely negotiated with scientists and pharmaceutical companies to change the “good practices” of clinical trials (randomization, double blind, and placebo) conducted to assess the effectiveness of new treatments in order to speed up access to such treatments [47].

#### *4.4. When patients want to establish their own diagnosis: science and life story*

The “chronic Lyme disease” controversy highlights a new step in the interference of the general population in the scientific field. We have already mentioned the importance of personal stories related to “chronic Lyme disease” posted on the Internet. Patients are claiming legitimacy for establishing their own diagnosis based on personal experience [17,48]. This is not an isolated example as associations of patients with electromagnetic hypersensitivity are striving to obtain official recognition of a disease associated with highly subjective symptoms that cannot be recognized and validated by physicians. Other examples are veterans convinced to have Gulf War syndrome or resident associations convinced to be physically affected by incinerators or motorway intersections. Confronted with an “invisible” disease, which signs and effects cannot be proven by scientific tools, the general population tries to gather testimonials and to undertake the “public socialization” of their own experiences to obtain recognition of a new disease [49].

This “patient-inherent legitimacy”, which pretends to present patients’ testimonials as sources of knowledge, was already in gestation among HIV-infected activists at the end of the 1980s [50]. It is now clearly advocated by associations campaigning for the recognition of a “chronic Lyme disease” presentation. When the France Lyme association was heard by the HCSP, they chose to present the testimonial of a physician believing to be suffering from Lyme disease for six years [44]. Similarly, in 2001, the relevant official authority of the United States investigated the effectiveness of a vaccine accused of causing “chronic Lyme disease”. During the hearings, the pharmaceutical company commercializing the vaccine presented the statistical results of a clinical trial while patients’ associations had people believing to be victims of this vaccine testifying [17]. Although this patients’ “pretentiousness” could upset

physicians, several studies suggest that physicians also tend to rather trust personal experiences than literature data (e.g., for the treatment of depression) [51,52].

## **5. Conclusion**

Far from being an abnormality, Lyme borreliosis represents an “archetypal” risk with numerous characteristics of modern risks and modern societies. Lyme borreliosis is an infectious risk resulting from the interactions between human activities and preexisting pathogens, that were until now unknown or forgotten. The “invisible” nature of Lyme borreliosis and some organizational factors delayed its media coverage.

Priority was then given to individual-based prevention, which requires understanding the general population’s perceptions: studies performed abroad suggest that these perceptions differ from that of experts (socially differentiated, based on personal stories instead of expert data, and subject to an “optimism bias”). Besides, one should also not forget the dilemmas faced by the general population contemplating a preventive approach to understand these perceptions.

The highly controversial issue of “chronic Lyme disease” highlights the modern disappointment in science and the numerous resulting controversies. Just like any other controversy, this controversy focuses on modern debates on science and shows the leveling of the general population’s and experts’ relative opinions, and the progressive interference of the former with expert matters.

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