Lived Experiences of Chronic Lyme Disease in Germany

Author: Ana Prundaru

Lund University
Sociology of Law Department

Master Thesis (RÄSM12)
Spring 2016

Supervisor: Dr. Måns Svensson
Examiner: Matthias Baier
“This battle cannot be won on a scientific front. We need to mount a sociopolitical offensive, but we are outnumbered and outgunned. We need reinforcements from outside our field."  

---

1 D. Parish (2016)
Table of Contents

I. Introduction  4
   Abstract  4
   Limitation  4
   Introduction  4

II. Literature Review  8
   Research Topic  8
   Research Problem  11

III. Research Design  15
   Research Questions  15
   Contextualization  15
   Research Design  16
   Methodology  18
   Data Collection  19
   Data Analysis  19
   Limitations  21

IV. Findings  22
   Overview  23
   Coping with Changes in Health Status  23
   Navigating Patient-Doctor Experiences  24
   Managing Systematic Challenges  24

V. Discussion  26
   Summary of Findings  27
   Social Construction of Illness  28
   Autonomy and Identity  30
   Patient Efforts to Influence Law  30

VI. Conclusion  31
   Bibliography  34
I. Introduction

Abstract
Chronic Lyme disease in Germany, although widely discussed in the political sphere, is not yet a legitimate illness in front of the law. Despite being classified as a (re)emerging threat to public health, fragmented regulatory approaches and the isolated nature of knowledge on Borrelia and co-infections represent major obstacles on curbing its growing impact on people's health.

This explorative thesis aims to add to the sociological discussion of chronic illness and healthcare reform, by shedding light on Lyme disease sufferers' experiences.

Limitation
One of the underlying purposes of this research is to understand how the under-regulation of Lyme disease and the social concept of chronic illness impact one another, next to impacting patients’ lived experiences of a chronic, invisible illness.

Therefore, the thesis does not claim to be in any way exhaustive.

Introduction
In this thesis, based on German patient reports, the significance of law for acknowledging chronic Lyme disease and filling healthcare gaps related to diagnosis and treatment will be presented from a socio-legal perspective. Thereby, in addition to analyzing patient reports through the lense of critical theory models, the image of law in the eyes of the patients will be discussed.

Legal consciousness essentially describes a society's construction of legality, as well as their attitude toward a social environment. In order to understand legal consciousness of chronically ill Lyme disease sufferers, I will study their reports on doctors’ behavior, diagnostic and treatment approaches, hospital behavior, as well as any behavior by authorities, tasked to decide on disability payments.

2 A Harms, C Dehio (2012)
3 Ibid.
4 M Getting (1990)
First, it is necessary to understand what Lyme disease is. The most common vector borne disease, Lyme disease is a term given to describe a multi-systemic diseases caused by the bacterium Borrelia burgdorferi and co-infections. Historically, it is recognized to be responsible for trench fever, which greatly impacted Napoleon’s Grand Army, as well as hundreds of thousands of soldiers in France during the First World War. Clinical manifestations range from bull’s eye rash and facial paralysis in acute stages, to arthritis, neuro-degenerative and circulatory issues in later stages. These intracellular pathogens are unique in the sense that they employ sophisticated methods to manipulate host cells, achieve immune evasion and thanks to their bio-film shedding and adapting techniques, resist conventional mono-therapies with antibiotics.

Despite many calls for action, the apparent hesitation of the European Union to agree on coordinated measures on Lyme disease could in part be explained by a view that is vested in structural functionalism and in Parson's sick role model, in which it is accepted that medical authority is unlikely to be exploited for financial gain, because institutionalized expectations would ensure doctors conducted themselves in ethical manners.

This attitude can also be explained by the fact that Lyme disease issues have largely been addressed from the perspectives of healthcare providers, lawmakers and interested parties, thereby leaving out patient input. According to Freidson, medicine is embedded in an ideology and is a wielder of power and control. Although chronic illness has not been as thoroughly studied as other medical topics, work from related sociological sub-branches can be taken into consideration to address illness as a deviance, medical accountability, conflicts of interests and injustices in healthcare coverage, to name a few things.

---

5 W. Byam, L. Lloyd (1920)  
6 M Almoussa (2015)  
7 A Harms, C Dehio (2012)  
8 A Rizzoli (2011)  
9 T Parsons (1954)  
10 Freidson (1970)  
11 D Mechanic, D McAlpine (2010)
According to a recent wide-ranging survey by the patient advocacy organization LymeDisease.org, people are diagnosed with Lyme disease six times more often than with HIV/AIDS and 1 1/2 times more often than breast cancer\textsuperscript{12}. These statistics speak for a potential threat to public health, unless proper legal actions are taken. Further, Lyme disease sufferers more bad physical days than patients with cancer, depression and cardiovascular diseases and score worse mentally and physically than heart disease and cancer patients,\textsuperscript{13} in addition to being five times more likely to go to doctors and twice as likely to be seen in emergency departments than the general population.

Despite these debilitating effects of tick-borne infections, European legislative action propelling coordinated measures of surveillance and management are lacking, while similar laws exist for other infectious disease such as HIV\textsuperscript{14}.

Foucault, who strived for objectivity and emphasis on measurement, took a chief interest in the social transformation that birthed modern medical advances. He showed the relationship between law and elements outside it\textsuperscript{15}, while correctly predicting healthcare cannot cover the entire needs of individuals in terms of health\textsuperscript{16}. Most importantly, Foucault demonstrated the micro-physics of power constitutive of modern social control, leading social reforms to partake of the logic of control\textsuperscript{17}. In line with him, Marianne Constable demonstrated that laws of modern states are in fact policies, concerned with order of populations and informed by regularities and interests depicted by human sciences\textsuperscript{18}.

When comparing patient reports to the treatment recommendation by European Concerned Action on Lyme Borreliosis\textsuperscript{19}, the frustrating conclusion is that these institutions appear to present a significantly downplayed version of the severity of improperly treated Lyme disease. Considering human rights protection is a key priority under Germany's Basic Law\textsuperscript{20}, it is surprising that no legal actions were so far taken in favor of patients.

\textsuperscript{12} https://www.lymedisease.org/lyme-basics/lyme-disease/about-lyme/
\textsuperscript{13} L Johnson et al (2014)
\textsuperscript{14} Communication from the Commission to the European Parliament (2009)
\textsuperscript{15} B Golder (2009)
\textsuperscript{16} M Foucault (2000)
\textsuperscript{17} M Foucault (1977)
\textsuperscript{18} M Constable (2005)
\textsuperscript{19} http://www.eucalb.com/
\textsuperscript{20} https://www.bundestag.de/blob/284870/ce0d03414872b427e57fcb703634dcd/basic_law-data.pdf
Legal positivists such as John Austin\textsuperscript{21}, prescribe jurisprudence, where the lawmaker shows his will to legislate a topic, thus morality plays little role in norm setting. Therefore, as much as the healthcare gaps in Lyme disease may seem morally repulsive, without a written law, patients' feelings fall short.

To be fair, because healthcare is predominately a national matter, minimum standards exist to protect essential health and safety interests. According to Art. 6, Par. (a) and Art.168, Par 7 TFEU, the EU has limited competences in healthcare, taking on complementation roles to national healthcare\textsuperscript{22}. Based on Art. 35 of the Charter of Fundamental Rights of the European Union, all EU policies should take into account human health protection. The European Parliament recommends monitoring of diseases when a Member State warrants it, for instance in epidemiological situations, but such situations are not defined\textsuperscript{23}. A recent European Centre for Disease Prevention and Control report found voluntary reporting of Lyme cases in only five Member States\textsuperscript{24}.

\textsuperscript{21} M Freeman (2012)
\textsuperscript{22} Consolidated version of the Treaty on the Functioning of the European Union (2012)
\textsuperscript{23} Directive 2003/99/EC
\textsuperscript{24} ECD Meeting Report (2011)
II. Literature Review

Research Topic
Health problems amount to one of the most serious and costliest social issues\(^{25}\) and of great significance are chronic illnesses, which affect more and more people\(^ {26}\). Many studies exist that assess relationships between law and social change, however there are not many on healthcare and social welfare, especially when it comes to chronic illness. This thesis will attempt to reproduce the picture of law by Lyme disease patients and answer the question regarding the significance of law in the improvement the situation of chronic Lyme disease in Germany.

Laws are systems of rules that are based on customs and traditions, influencing everyday life\(^ {27}\). Legal consciousness narratives are separate characterizations of law in society, drawn upon from people's lives and representing both a characteristic individual response to law and a cultural schema that makes sense of law at structural level\(^ {28}\). Analysis of legal consciousness can help learn whether for some groups law is a mode of protection, or even oppression.

According to Hans Kelsen, positive law not only regulates matters, but it creates an obligation\(^ {29}\), thus the law makes moral claims on the people. Applying this thought to a potential Lyme disease law, such a legal system would give patients the privilege to proper treatment and give healthcare professionals the duty to act according to a framework regarding Lyme disease management.

But despite a universally recognized right to healthcare, from a positivist law point it is not easy to answer the question of entitlement of patients to certain healthcare and certain welfare support, since these rights are conditional upon finite resources\(^ {30}\). The law would then have to decide, not only whether based on existing data, it is justified to legislate on Lyme disease, but also, what the adequate level of support it is prepared to afford for Lyme disease sufferers.

\(^{25}\) N Dresscher (2011)  
\(^{26}\) M Derryberry (2004)  
\(^{27}\) H Arthurs (1996)  
\(^{28}\) P Ewick (1998)  
\(^{29}\) H Kelsen (1928)  
\(^{30}\) Epstein (1999)
German lawmakers may find inspiration based on Ehrlich's, living law, which, although it does not address conflicts of interests, is broader in scope, as it represents the legal reality, includes a group's values and norms and traces the law based on people's interactions. These norms may or may not coincide with the positive law. To name some examples, although the German law has not officially acknowledged chronic Lyme disease as invalidating and deadly and in need of long-term antibiotic therapy, some doctors treat it as such and singular communities provide financial support to patients.

In Europe, approximately 65,500 patients annually are infected by Borrelia and co-infections, though occurrences are likely considerably higher, due in part to lacking mandatory notification rules and doctors’ difficulty to diagnose it. It is safe to say scattered approaches to Lyme disease throughout the European Union contribute to underreporting of cases, which in turn shapes public opinion and leads to misrepresentation of its danger.

When it comes to developing more reliable tests, it must be said that there are roughly a hundred Lyme disease causing strains of bacteria, yet current diagnostic are restricted to a handful bacteria and are not nearly as accurate as they should be to rule out an infection. On top of that, medical bias in research and treatment contribute to the under-regulation of tick-borne diseases.

Within the social model of health, which analyses interrelatedness of health with people’s social environments, law is one of the major determinants of health and illness. Limited leadership by governments impacts social awareness, shaping the public's view on the seriousness of the disease. Feeling neglected by the law and healthcare system, patients throughout Germany have taken to the streets in strings of protests on the lack of Lyme disease regulation at national level.

31 E Ehrlich (1962)
32 Rizzoli (2011)
33 C Bean (2008)
34 A Caruana (2016)
35 Lo B, Field MJ (2009)
36 J Germov (2009)
The data analysis in this thesis suggests that on average, German doctors score poorly when it comes to detecting tick-borne illnesses, let alone putting together individualized treatment plans.

On one hand, doctors are faced with ethical barriers, as they are bound by normative ethics and to put it simply, they cannot treat a patient whose illness is not properly regulated. On the other hand, they are overwhelmed by limited information on different types of Lyme disease causing bacteria, their co-infections and designing complicated long-term treatments.

Neither positive law, nor living law can fully acknowledge power structures, conflicts of interests and biases in healthcare, nor can they give clear answers on how to balance interests and define rights and duties. One has to consider the politicization of Lyme disease and the inequalities experienced by patients, who shoulder the burden of proof of their illness, in the face of lacking research, coordinated measures, reliable diagnostic tools and good treatment results. This is why various conflict theoretical perspectives can be useful in describing observations reported by patients in their relationships with doctors and the legal system.

Since there are no valid national guidelines, German doctors often turn to the recently unveiled as corrupt Infectious Disease Society of America (IDSA) guidelines for treatment advice, despite evidence towards its bias. Instead of uncovering the infection as the cause of health problems, almost all surveyed patients were first diagnosed with idiopathic cases of chronic fatigue, fibromyalgia, arthritis, heart disease, autoimmune diseases, or multiple sclerosis. Thereby, they lost important time, allowing their infection to become chronic.

According to Conrad, illnesses are socially constructed at the experiential level on one hand and influenced by interested parties on the other. What is more, certain illnesses are embedded with cultural meaning, which considerably shapes how parts of society reflect on those who are ill.

38 G Smith (1993)
39 L Johnson (2010)
40 P Conrad, K Barker (2010)
Thus, there are illnesses, which are well understood and recognized in our society, as there is a lot of historically rooted experience with them. Such is the case for example with tuberculosis. Then there are those that are very poorly understood, partially due to lack of research and lack of reliable tests, which is the case for Lyme disease. Sociology of law and medical sociology provide essential input, which contributes to a better understanding of how substantive and procedural matters in healthcare are shaped by politics and social arrangements. To give an example, the IDSA board members had ties to insurance companies, explaining why they rejected acknowledging certain symptoms as caused by Lyme and accepting the existence of chronic Lyme. It can be concluded that the law provides inadequate protection to chronically ill Lyme disease patients, even going as far as to say the inaction represents a form of denial of this disease.

Research Problem

Healthcare providers represent social structures, whose makeup and management are influenced by law and ultimately create varying experiences for doctors and patients. Based on critical theoretical thought, doctors are agents of social control, with various loyalties and ethical beliefs, while patients must subordinate, in order to receive treatment.

Where legal provisions on a disease are lacking, one can argue that doctors gain margin of discretion in deciding on a patient's treatment or sickness benefits, while patients lose power to protect their interests.

While social inequality theories have widely addressed healthcare gaps like unequal access to healthcare, in the case of Lyme disease, which impacts people equally across social classes, the main issue appears to be corporate control of healthcare, which undermines the progress toward unbiased medical guidelines and quality healthcare.

---

41 M Delaney (2016)
42 J Quadano (2005)
43 J Metzi (2014)
What it means to be labeled incorrectly, or worse yet, be labeled healthy, while being seriously impacted, has been discussed by Freidson, who recognized the tangible social consequences of an illness label and urged sociologists to uncover how symptoms become to be labeled as an illness in the first place.\textsuperscript{45}

As such, he assumes patients and doctors come from different socio-cultural worlds, which shapes their conceptions, meaning the same phenomenon can have different relevance and be interpreted differently by both sides.

Moreover, patient-doctor experiences are shaped by normative ethical theories, whose end goal is to reach rational judgments, by applying actions that bring about a good end result.\textsuperscript{46} In principle then, both patient and doctor have the same goal - to get the patient healthy - but in the face of conflicting data on Lyme disease, there does not seem to be one solid solution.

If Lyme disease was to be categorized as a social deviance, it would consequently grant sufferers a certain freedom from social responsibilities, explicit in the sick role construct.\textsuperscript{47} As societies are founded on liberal ideas of individual responsibility and competition, freedom from social obligations is generally discouraged.\textsuperscript{48} Thus, chronic Lyme disease sufferers who become disadvantaged due to loss of income, are, according to my data analysis - more likely to be scrutinized and suspected of taking advantage of the social support system, than people with acknowledged disabilities, when they seek disability support or help with treatment costs.

Patients are more often than not left out from Lyme disease regulation discussions, despite holding key information on medical, legal and social pitfalls. For instance, while the IDSA was revising its guidelines for Lyme disease treatment, not a single Lyme disease physician or patient was allowed on the review panel.\textsuperscript{49} Patient advocates therefore continue to stress the risks involving costs and quality of healthcare, due to the doctors’ powerful autonomy to practice medicine as they feel fit and the resulting lack of accountability.\textsuperscript{50}

\textsuperscript{45} E Freidson (1970)  
\textsuperscript{46} G Smith (1998)  
\textsuperscript{47} T Parsons (1951)  
\textsuperscript{48} C Barnes, M Oliver (1993)  
\textsuperscript{49} https://www.lymedisease.org/get-involved/take-action/why-we-protest-against-the-idsa/  
\textsuperscript{50} D Mechanic (2006)
Based on positivist theories of law, it seems important to have laws to set up checks and balancing systems to counteract such risks and also legitimize the disease. After all, laws hold the ultimate power to legitimize an illness, propel researches on curing and managing illnesses and strengthen medical providers’ accountability. This appears especially true in the case of chronic invisible illness, where laws can shape society's expectations on patients. Even soft laws, such as medical guidelines and ethical policies regulating chronic Lyme disease can immensely impact the ways medical professionals approach an illness and the extent to which funds are allocated toward rehabilitation, prevention of ill health and supporting patients with self-care, to name a few things.

Considering there are several calls for action on Lyme disease, it is disappointing to learn a patient-powered petition to Parliament for such a law has been struck down earlier this year. Although the official argumentation for this rejection has not been made public yet, based on my observations and the German patient advocacy group’s statement, this rejection seems to boil down to two main arguments: firstly, due to sparse large-scale research efforts and reliable tests, demonstrating a tangible danger for public health and secondly, various powerful stakeholders have cleverly utilized misinformed, or manipulative media and medical outlets to vehemently lobby against Lyme disease measures.

Doctors enjoy highest level of trust from lawmakers and patients, which from a functionalist perspective makes sense, but becomes problematic, considering they are accorded the right to regulate and evaluate their own conduct.

---

51 S Mehring (2015)
53 https://www.openpetition.de/petition/blog/schutz-fuer-patienten-mit-borreliose-und-co-infektionen
54 American Lyme Disease Foundation (2015)
55 K Browne (2006)
56 J Gabe et al (1994)
Germany has a number of scattered Lyme disease treatment guidelines, which rarely acknowledge chronic Lyme disease, or if they do, they brand it as Post Lyme syndrome, thereby falsely claiming the patients have rid themselves of the bacteria. Adding to the problematic handling of Lyme disease patients, the treatment guidelines offered by the “Deutsche Borreliosegesellschaft’ (German Lyme Disease Society) considerably differ from those put forth by the “Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften” (Consortium of Medical Expert Association), which raises the question of conflicts of interests once more and unnecessarily promotes uncertainty. Additionally, the treatment guidelines by the esteemed Robert Koch Institut, acknowledge, in theory, what they call a very rare form of tick-borne infection, but this view is far from being in line with the aforementioned statistics on yearly infections and seriousness of symptoms. Another problem is, based on these guidelines, Lyme disease is viewed predominately as an occupational hazard for foresters and veterinary doctors, amongst others. In addition, under chronic Lyme disease, only neuro-Lyme is listed, even though chronic forms can affect virtually any organ, such as Lyme-carditis. By providing such a narrow set of guidelines, people are left out, leading to missed diagnosis, with catastrophic consequences for doctors and patients.  

57 Robert Koch Institut (2013)  
58 Ibid
III. Research Design

Research Questions

Question 1
How does a sociological analysis of patient experiences explain the widespread gap in perception of chronic Lyme disease between doctors and patients?

Question 2
What is the significance of law, from the patients' point of view, in the improvement of diagnosis and treatment, as well as overall acknowledgement of chronic Lyme disease in Germany?

Contextualization
A social constructionist approach to illness is rooted in the conceptual distinction between disease, as the biological condition and illness, as the social meaning of the condition. In this thesis, the legal consciousness reflects how patients feel that law regulates their needs and how important law is in protecting their interests. The goal will be achieved, by first distilling the image of law presented by patients, who suffer from chronic Lyme disease.

While public perceptions of chronic illness are continuously evolving - thanks in part to movements by chronically ill - it must be stressed that sociological models to studying chronic illness have certain limitations and often are inadequate to fully understand the illness burden. Yet they are indispensable for lawmakers in deciding when and in how far, regulation is required for a social problem.

The first national study of chronic illness in the UK produced functional assessments of impairments based on the distinctions between impairment, disability and handicap. This typology has dominated sociological analysis and social policy ever since.

---

59 I. Eisenberg (1977)
60 A Harris (1971)
61 C Barnes, M Oliver (1993)
However, this approach remains unsatisfactory for many reasons, including the fact that the definition of disability, as the inability to perform an activity is dependent on each social group's understanding of normality, as well as temporal, cultural and situational factors.\(^{62}\)

In addition, impairments are oftentimes presented as the cause of handicap, which means they should be cured by medical intervention, which is not always realistic, for instance in the case of persisting chronic Lyme disease. Not all causes of chronic illness can be resolved and quality of life restored through medical intervention.\(^ {63}\)

Lastly and perhaps most importantly in this case, definitions of chronic illness often produce a barrier between disabled and the rest of society,\(^ {64}\) thereby only perpetuating oppression.\(^ {65}\) Yet, with chronic Lyme disease, there is already mistrust by doctors and society at large, even without - or perhaps due to lack of - legalization.

Based on the results of data analysis, throughout medical communities in Germany, there often appears to be a misinformed social meaning attached to chronic Lyme disease, namely that it is extremely rare and arrives as a result of post-treatment fatigue. Thus, while many German doctors are well meaning, based on lack of reliable resources and the public skepticism, they resort to assuming many of their Lyme disease patients are in fact not as ill as they claim to be.

On the other hand and in stark contrast to Parson’s perspective on the sick role, chronic Lyme disease patients are more often than not active in shaping their roles, although most go through similar negotiation process experiences in response to chronic illness, namely biographical disruption, treatment impact and adaptation.\(^ {66}\)

Bolough claims modern medicine dehumanizes patients, alienating self from body and warns of the consequences of professional dominance inherent in the medical systems, leading patients to be left out of decision-making.\(^ {67}\) This appears to be at least in part true for German Lyme patients, especially when it comes to patients attempting to seek long-term antibiotic treatment and going to several doctors, because many are unaware of the illness.

---

\(^{62}\) P Wood, N Badley (1978)
\(^{63}\) S Brisenden (1986)
\(^{64}\) I Zola (1982)
\(^{65}\) K Davis (1993)
\(^{66}\) M Bury (1997)
\(^{67}\) R Bologh (1981)
Primary care has struggled with maintaining continued personal relationship where one medical team takes responsibility for coordinating the patient’s needs, and this is more so in the case of invisible chronic illnesses. Another issue affecting the patient-doctor relationship relates to the manners in which healthcare topics are prioritized and structured, which impacts how doctors address various illnesses. Sociological studies have unveiled common causes the failure of governments to manage to provide quality healthcare while also curbing rising healthcare costs and raising doctors’ accountability. Such a cause is the opposition of stakeholders and especially medical doctors, to health reforms, due to potential financial losses accompanying modifications of healthcare laws.

The seeming reluctance of German regulators to address patient concerns and a potential epidemic could admittedly be falsely interpreted to mean the illness effect is not serious enough to require a action. This situation worsens rising medical costs, loss of economic manpower, unnecessary suffering and financial losses. Now, more than ever, patients are in a unique position to influence lawmakers and shift public perception of chronic Lyme disease, for instance by using digital media to share their experiences and collect signatures to address the government. As noted by Bury, patients can draw on experiences to catalyze change, on top of self-managing their situation and working toward a health come-back.

Research Design
It was decided to adopt a qualitative research design and more exactly summative content analysis, in order to give a realistic picture of lived illness experiences. Qualitative inquiries have regularly been utilized to analyze patient-centered healthcare, with the aim of seeing whether treatment was geared to produce most effective outcomes based on integration of conventional understanding of disease with patients’ unique experience of illness.
Barely any comprehensive and longitudinal studies on lived experiences with chronic Lyme disease exist in Europe, despite the fact that such research would seem helpful in assessing long-term needs of patients and giving an insight into the devastating effects of untreated parasitic infections.

A number of quantitative studies exist on chronic illness in general, which focus on such topics as the impact of chronic illness on social participation and even fewer on Lyme disease in particular. Quantitative studies are limited when it comes to taking into account emotional, practical, financial barriers, as well as systematic barriers adding to the illness burden.

However, one recent quantitative study on chronic illness attempted to draft measurement scale for the social participation of chronically ill, which used a narrow set of characteristics that specify social participation as a positive experience with a list of characteristics, including contribution to society and social contact. Gammon and Nolan performed one of the largest quantitative studies on chronic illness in 2004, which unsurprisingly yielded results showing that these individuals had a rough time participating in social life. The problem is that these types of studies do not look into the contributions of doctors and legal professionals in the participation progress of patients in society and rather in an artificial manner regard the patients isolated from their environment, which is why a qualitative study was chosen here.

Methodology

Statements by twenty chronically ill Lyme disease patients were collected from a major Lyme disease discussion board in Germany during the months of March and April and analyzed according to systematic content analysis methods.

---

78 N Metcalf, L Dean (2016)
79 E Adamson (2004)
80 L Johnson (2014)
82 N Gannon (2006)
83 http://forum.onlylyme-aktion.org/
84 K Hausser, P Mayring et al. (1985)
Despite the fact that Lyme disease discussion boards exist throughout Europe\(^8^5\) and petitions for Lyme disease regulations allowing more accurate tests and effective treatment protocols can be found from UK\(^8^6\) to Austria,\(^8^7\) I settled on researching patient experiences in Germany, because I was stunned by the limited research on social accounts of Lyme disease in Germany. Content analysis was chosen, due to the fact that it enables describing a phenomenon, which has limited research literature. It enabled complete emergence in the experiences of patients. Therefore, instead of using preconceived categories, I deducted them from the collected data\(^8^8\).

Thanks to its flexibility\(^8^9\), this research method is widely used in health studies and has the advantage that it extracts data, based on information stated by patients in their own words, without outside influence, such as in interview methods.

The analysis was performed based on Meyring’s model, which defined qualitative content analysis as empirical analysis of contents within their context of communication, following content analytical rules and step by step models, without rash quantification\(^9^0\).

Patient reports were subsequently grouped into categories and carefully revised within the deductive process of analysis\(^9^1\).

Data Collection
Based on purposive sampling of self-reported chronic Lyme disease patients, a summative content analysis was applied to statements by twenty individuals, which I extracted from a major German discussion board focused on Lyme disease\(^9^2\). Each patient's data ranged from a paragraph, to two pages long. As mentioned, the specific criteria for inclusion was that the forum posters resided in Germany and suffered from Lyme disease for more than six months and were either diagnosed through a medical professional, or by a laboratory.

\(^{8^5}\) http://www.lymenet europe.org/forum/
\(^{8^6}\) D Demetriou, Petition, UK Government and Parliament (2016)
\(^{8^7}\) Austrian Petition to Health Minister Alois Stoger (2016)
\(^{8^8}\) N Kondracki, N Wellman (2002)
\(^{8^9}\) P Cavanagh (1997)
\(^{9^0}\) K Hausser, P Mayring et al (1985)
\(^{9^1}\) S Ballstaedt, H Mandl et al (1981)
\(^{9^2}\) http://forum. onlylyme-aktion.org/.
Data Analysis

Data was read several times and word for word, so as to highlight commonalities and understand the entirety of the whole experience picture. Statements were assigned codes, which fell into different categories, such as doctors’ beliefs on chronic Lyme disease and patients’ self-management and coping strategies. Afterward, I grouped statements into common themes, which will be discussed in the following. A narrative, descriptive and phenomenological methodology was employed to interpret the statements. Patients' experiences with doctors will be filtered through the lenses of systematic interactionist and functionalist perspectives, to gain an in-depth understanding of challenges encountered.

Ethical issues on privacy and confidentiality were taken into consideration, since patients talk about very personal issues. Therefore, the research was strongly influenced by the three core principles of ethics from The Belmont Report, namely respect for persons, beneficence and justice. In order to safeguard their rights, I did not use their usernames and instead allocated numerical digits to each individual.

Limitations

While one could argue that analyzing patients' experiences with the scope of distilling legal consciousness may suffer from reliability issues, one can say that these experiences toward legality are not solely personal, but reflect a greater patient groups' attitude, as patients throughout Germany are likely to go through similar emotions, when dealing with the law. In addition, a person's view is never isolated from the society that surrounds the person.

Thus, this analysis also contributes to explaining the manners in which legality is constructed in a social setting. Similarly, although legal consciousness is a construct that has been historically seen as unstable, it is exactly due to its changing nature, its dependency on cultural and social change that makes it capable to inform legislation, by paying attention to the ways law is interpreted by Lyme disease patients, as they engage with and challenge the law. It is therefore an indispensable starting point to assess the necessity of socio-legal change.

93 M Miles, A Huberman (1994)
94 R Tesch (1990)
95 C Kohler Riessman (2000)
96 E Guba, Y Lincoln (1994)
97 Belmont Report (1979)
The question of trustworthiness of qualitative inquiry is frequently raised.\textsuperscript{98} Because the accuracy of findings is at the core of the research project,\textsuperscript{99} the work has been conducted based on principle of truth and honesty.

In addition, a colorful variety of patients was included, to avoid bias and much effort was put into choosing such forum members, who were regarded as helpful contributors and hence appeared to exude a certain level of trust within the online community.

Moreover, throughout the data analysis process, I made sure to regularly acknowledge my own perspective as separate from sociological reflections on results obtained from this patient sample, thereby making sure to not let personal opinions get in the way of a scientific research.\textsuperscript{100}

Lastly, the data interpretations have been double-checked and feedback was sought out from family and friends to ensure neutrality.\textsuperscript{101}

Despite these efforts however, it has to be cautioned that, taking into account the relatively small sample of participants and the short research period, the results may not be easily be generalized to other chronic Lyme disease sufferers, such as those outside Germany.

Another possible limitation is the strategic device of narrative\textsuperscript{102}, which often can be performative in character.\textsuperscript{103} The same caution is due for such individuals who display a social desirability effect, by writing something perceived by the community as desirable, instead of stating the truth\textsuperscript{104}. However, such situations appear highly unlikely, since one can argue that since participants are anonymous, they have no reason to state untruthful facts.

\textsuperscript{98} E Guba, Y Lincoln (1994)
\textsuperscript{99} A Clayton, T Thorne (2000)
\textsuperscript{100} T Koch, A Harrington (1998)
\textsuperscript{101} S Halldorsdottir (2000)
\textsuperscript{102} C Kohler Riessman (1990)
\textsuperscript{103} M Bury (1997)
\textsuperscript{104} A Bryman (2008)
IV. Findings

Overview
The discussion board at the centre of this research emerged as a place where patients confined in one another experiences of life with chronic Lyme disease, gave doctor recommendations and shared strategic advice related to obtaining treatment, correcting false health reports, or challenging rejected disability decisions. Three major themes emerged from participants’ description of their experiences, which will be briefly described below and discussed using socio-legal theories in the next chapter.

Coping with Changes in Health Status
A young female patient described the anxiety and frustration of her year-long, undiagnosed and poorly treated health struggles, which finally lead to a Lyme disease diagnosis. She stated that, based on the widespread denial of chronic Lyme disease she experienced, she was afraid to be labeled as an emotionally unstable woman and become unable to care for her child. Her doctors did not take her ailments seriously, leading her to navigate work, life and health challenges on her own and without antibiotic treatment.

Another patient saw a doctor in the hopes of receiving care for debilitating chronic fatigue during long-term antibiotic treatment. The doctor recommended a glass of champagne in the morning, which understandably, the patient took as an attempt to ridicule the patient and a sign of poor awareness of crippling effects of chronic fatigue.

A different patient, who hoped for support in tackling joint pain reported his doctor claimed the diagnosis of Lyme disease should be legally prohibited like the far-right party NPD.

A patient, who was in a rehabilitation clinic for a myriad of symptoms, took part in one Nordic Walking class. This lead to the discharge note claiming he was healthy, which in turn endangered the disability status. Because chronic Lyme disease sufferers can have days when they are functional, this patient was able to participate on one occasion, but was ill again the following days. However, doctors concluded if
he was healthy to participate once, he was healthy enough to take part in social activities and thus suggested he had an emotional ailment. Understandably, this patient was very upset and fearful of his future, as it appeared doctors did not understand the nature of the illness and the effort it took to participate in one class and the exhaustion and pain he felt in the following days from the class. Doctors not only were unhelpful addressing his short-term needs, but also endangered his disability status.

One patient initially expressed gratefulness at the seemingly neutral patient help hotline and encouraged other chronic Lyme disease sufferers to make use of this service. However, as others have pointed out, it turns out that the services are not as neutral as they appear, since the company offering them has strong ties to pharmaceutical and insurance companies in Germany, having represented their interests for many years prior to offering the patient support services. These findings were understandably met with frustration, but not surprise, as they represented yet another situation of conflicts of interests that represent a hurdle for patients on their road to legitimization.

Negative Patient-Doctor Experiences
A number of female patients reported feeling discriminated due to their gender and not being taken seriously as a result. One female patient asked her doctor for antibiotics, as her symptoms did not go away on their own. The doctor answered she shall go on vacation. Another patient reported a similar dismissive attitude that reflected a slightly misogynist view, advising the patient to relax.

A different patient, by quoting recent scientific researches, questioned her doctor’s outdated treatment plan that recent research agrees to be inadequate for chronic Lyme disease. Thereby, the patient noted that the doctor felt personally attacked and raised his voice at her, telling her she shall then go to these researchers for treatment if she didn’t like his approach. Two more patients commented having had similar experiences, which they attributed to narrow-mindedness.

Two patients mentioned being embroidered lawsuits with hospitals that wrote a false or misleading discharge report, which endangered their disability status.
A medical specialist, despite observing muscle weakness in a sero-positive female patient, told her he was not sure what the causes were, therefore she probably had no serious issue. The patient, feeling overwhelmed at this ignorant remark, started to cry, whereby the doctor said, he knew she was just depressed and made all the symptoms up. His colleague then passed by and the doctor proceeded to point to his female patient and ridicule her, stating it was more likely for her to fly to the moon than that she had chronic Lyme disease.

The most unprofessional statement I came across was from a doctor who called himself a Lyme disease specialist and said women who say they have Lyme disease just do so, in order to have a topic to talk about during coffee breaks.

Managing systematic challenges
A number of patients had difficulties getting past the disability expert, due to the fact that many so-called experts dismiss even sero-positive individuals. As one patient said, his expert told him, most of the population tested positive, but most people were healthy. Thus, he concluded, the patient was likely also healthy and only pretending to be ill to receive payments.

Two patients reported feeling as if disability experts did everything in their power to refute other doctors’ reports that connected their ailments with untreated tick-borne infections. This lead to those patients suing and having to go through extensive and sometimes invasive tests to prove their suffering was indeed caused by a bacterial, likely tick-borne infection.

Another patient stressed the medical and governmental hurdles in receiving disability payments, despite his profession being one of the acknowledged professions where Lyme disease was seen as an occupational hazard. The patient stressed that the difficulty was in finding a doctor who diagnosed his arthritis as a direct outcome of a tick-borne infection and later receiving court mandated disability funds for a limited time, since under the law, tick-borne infections are only seen as short-term and curable.

The majority of patients have expressed lack of faith in the medical system, due to having to accept a misdiagnosis and inadequate treatment, in order to receive disability payments.
One patient reported feeling upset of receiving Qi Gong therapy in hospital, instead of having his Lyme disease infection addressed. However, the patient eventually accepted that it was best to play along with the diagnosis of burn out, in order to receive the medical report that said the patient was unable to work and in need of financial assistance.

Practical difficulties were encountered by almost all patients and were related to getting to and from doctors and managing treatment regimes in times of lowered abilities to self-care.

A patient who was bedridden had difficulties organizing antibiotics infusions from home, as few States permit such services. No hospital offered such treatment either, as long-term antibiotic treatment is rarely seen as a first choice of addressing illnesses, especially one that was not officially acknowledged.

In the end, after fighting for governmental approval for home-care, the patient was not able to find a doctor to make the infusion, as palliative care organizations were only allowed to connect infusions, but not place the needle. Thus, the patient was forced to wait until feeling better, to go to the doctor’s for weekly treatments. A Picc line could have been a solution, however considering the risk of infection, the patient decided against it.
V. Discussion

Summary of Findings
Summed up under socially constructed view of illness and identity issues, the patients' experiences enabled an unprecedented insight into the inner lives of chronically ill German Lyme sufferers, which, in the vein of Sartre's progressive-regressive method\textsuperscript{105}, gives the chance of connecting biography to its social context, as well as seeing social problems through the accounts of affected individuals. From the analysis of patient experiences, it is deduced that understandably, patients' lifeworld\textsuperscript{106} ideas of identity were essentially broken apart upon their diagnosis of chronic Lyme disease. However, the act of communicating with other patients on the forum and doing so on a non-hierarchical level and without being met with suspicion - unlike in doctor's offices - appears to guide patients toward reconstructing a new self, or at least gain some comfort and control over their lives. Habermas' framework is very helpful here in understanding the results, as he rightfully noted that the lifeworld is the medium for nurturing personality and social integration.\textsuperscript{107}

The data analysis suggested an unbearable difficulty in dealing regularly with hierarchical structures of patient-doctor relationships, as well as obtaining adequate care, in the light of symptoms without objectively agreed upon legal basis. On the other hand, the data analysis also showed that these patients' cases posed great challenges to doctors' notions of what constitutes diseases.

Thus, the significance of law in regulating everyday lives of chronically ill Lyme disease patients is extremely high, based on patient reports. While a number of patients were disillusioned by the law - not least due to the rejected petition to the Parliament in early 2016 - most patients appear to hold hope that justice will be done. And so, perhaps because there are few choices left to improve their health, most patients continue to campaign for awareness, online or on the streets. However, without a Lyme disease law, patients must make the choice between living as an ill person and allowing medical procedures to dominate their lives - whereby lifeworld plays little role-, or living as a person managing a disease.

\textsuperscript{105} R Farrar (2000)
\textsuperscript{106} F Collyer (2015)
\textsuperscript{107} ibid.
As for the perception of chronic Lyme disease gap between doctors and patients, unless a doctor has experienced Lyme disease, it is unlikely to empathize fully with patients' struggles. This leads doctors to minimize patients' symptoms. Positive experiences were reported in context with attentive and empathetic treatment by doctors and nurses. The lack of allocated time for each patient also played a role in understanding the full picture of this illness and there appeared to be little interest on doctors' side to research the disease on their own time.

Within the current climate of scattered information and lack of enforceable regulations determining best approaches for medical professionals, the patient risks being dismissed as troublesome, while doctors may appear incompetent. Patients find that the lack of a Lyme Disease Regulation threatens not only their health, but also questions their credibility. Data findings showed patients experienced substandard treatment, confusion over unreliable laboratory testing for Lyme strains and poor doctor-patient relationships, which lead to disillusionment with law and healthcare. Another emerging problem was the lack of specialized hospitals and the under equipped doctor's offices and medical centers to properly address needs of chronically ill and severely disabled Lyme disease patients.

In conclusion, the law that is supposed to deliver justice\textsuperscript{108}, struggles to address sociological phenomenon related to chronic Lyme disease, including long-term disability.

Social Construction of Illness

Social constructionism is helpful in explaining the patient accounts of chronic illness, as these frameworks acknowledge that diseases cannot be seen separate from society, values and culture. And so, each patient has a unique relationship with his disability and with the disability in context of his or her social environment. The discussion board was again helpful in guiding newly diagnosed patients and shaping assumptions of chronic illness. Although disability is well regulated in Germany, chronic Lyme disease is not usually considered to be a disabling condition by law or society. Thus, counseling, treatment, rehabilitation and work conditions are not geared toward these patients.

\textsuperscript{108} R Benakar (2015)
Brown noted that medicine plays a dominant part in construction of illness through direct interaction\textsuperscript{109} and that social construction of illness is dynamically correlated to social constructors and society.

Data analysis suggested that patients rather unsuccessfully attempted to convince doctors, lawmakers and - to somewhat more success - the general public of the menace of chronic Lyme disease. Medical professionals, rather than patients, are furthering the Lyme disease discussion, thereby leaving out key participants, who have insider information. Among others, data stressed the urgent need to adjust social constructions of illness to include chronic, invisible illnesses, by highlighting their destructive force and the part played by systematic issues in medical and legal systems.

Epstein underscored the politics of knowledge by demonstrating how the science regarding the cause and treatment of HIV/AIDS is best understood as an amalgam that is constructed and contested by different constituencies like scientists, doctors, drug companies and activists rather than the outcome of pure science.\textsuperscript{110}

A similar observation resulted from this research for chronic Lyme disease. Next to essential truths uncovered by extensive research, the society’s knowledge on Lyme disease determines the outcome of political negotiations.

Factors that seem to be responsible for the present social construction of chronic Lyme disease are non-prioritization of chronic Lyme disease sufferers’ needs by the government, due in part to lacking detailed and long-term research on chronic Lyme disease, a poor understanding of the biology of borrelia and co-infections, as well as unreliable tests that determine whether someone is infected.

Auguste Comte’s and Herbert Spencer’s structural functionalism describes a framework concerned with building a theory on society as a whole, whose parts interact to promote stability\textsuperscript{111}. Applying this functionalist viewpoint to the patient data, it is clearly doctors, along with lawmakers and stakeholders, who are main actors to propel medical innovation, as they are the experts and questioning them would increase instability in society.

\textsuperscript{109} P Brown (1995)
\textsuperscript{110} P Conrad, K Barker (2010)
\textsuperscript{111} S Appelrouth (2005)
It is then only when doctors and lawmakers view chronic Lyme disease as sufficiently dangerous that regulatory actions are taken. Although this observation does not mean that patients' awareness actions are fully neglected, it explains part of the power struggle going on, especially when it comes to which group draws the line that separates acceptable from unacceptable levels of disease. From patients' viewpoint, the breaking point has long arrived, as many have been rendered disabled and housebound with insufferable and progressing symptoms, but this is not true from the lawmaker's perspective, which believes there is not high enough levels of illness that may interrupt normal social functioning.\textsuperscript{112}

**Autonomy and Identity**

A feminist analysis is helpful in interpreting the results on shaping one's identity throughout chronic illness, not only because most chronic Lyme disease patients are women\textsuperscript{113} but also because feminist enquiry deals with various issues on cultural representations of the body. Based on data analysis, doctors' behavior appeared to depend highly on a socially constructed idea of disease and femininity, something that has been demonstrated by various feminist theorists, claiming that both the female body and the disabled body are viewed as deviant and inferior, sometimes excluded from full participation in public and defined in opposition to a valued norm of the male, able-bodied group\textsuperscript{114}. Data analysis showed patients experienced different types of oppression, such as in being excluded from society due to their disease and being denied proper treatment, due to the unrecognized nature of their illness. Another problem observed was the misunderstandings of society on acknowledging someone as chronically ill, who looked and acted healthy, even if it was for a short while. In a way, chronically ill Lyme sufferers may not be as openly marginalized as visible disabled people in a society that idealizes physical and mental fitness, but they are still daily reminded of their otherness.\textsuperscript{115} This is also why chronically ill Lyme patients feel accepted neither in the public sphere, nor in the medical community.

\textsuperscript{112} I Lubkin (2006)  
\textsuperscript{113} G Wormser (2008)  
\textsuperscript{114} R Garland-Thompson (1997)  
\textsuperscript{115} Wendell (1997)
It is then understandable that patients are often compelled to break the stigma and share their own account of their personal and social reality as a chronically ill person. Many showed amazing resilience in coping with the illness burden, managing daily tasks and joining other patients in filling experienced healthcare gaps. Data analysis showed patients still have faith in law, alas they view legal progress as a long-term matter, bracing for an uphill battle through potential conflicts of interests, until proper research and treatment would be enabled. Many patients learned to bounce back fast from misdiagnosis and stigmatization by medical professionals, not least due to online support systems. Coping and adaptation had to be flexible, day-to-day basis, depending on symptoms and available infrastructure\textsuperscript{116}. Patients actively participated in the construction of selfhood and attempted to change their own social worlds, via ongoing social interaction\textsuperscript{117}.

\textsuperscript{116} R Lyons (1998)  
\textsuperscript{117} H Blumer (1969)
VI. Conclusion

While it is not rare for laws to lag behind social change\textsuperscript{118}, in terms of German patients' opinions, Lyme disease emerged as one of the most neglected public health issues\textsuperscript{119}. Lyme disease patients engage with the law on a near daily basis, as they attempt to acquire leave of absences for work, convince insurances to pay for prolonged hospital stays and expensive treatments and obtain invalidity status for rent.

These experiences no doubt shape their image of law and based on the data analysis showing various layers of patients' relations with the law, the vast majority felt left behind by the law. Thus, their legal consciousness demonstrates that patients with chronic Lyme have little faith in current legal and medical landscapes, therefore feeling the need to take matters into their own hand, to ensure better care for future generations.

A power imbalance between doctors and patients could be observed, as it is doctors who have the final say whether patients receive sick notes, proper treatments and rehabilitation programs. Patients appeared hopeful that, at least on the long run, German law will step in to acknowledge their illness and ultimately mitigate this power imbalance.

In line with the comments made by Ewick and Silbey: "\textit{The law is what people do about the law},"\textsuperscript{120} these patients, despite already overburdened by their symptoms and challenges in managing everyday life, more often than not, gathered to protest lack of tick-born illness awareness, poor medical education on Lyme disease and little support systems on Lyme disease.

For the patients' sake, one can only hope that influential individuals, who have a personal interest in furthering our understanding Lyme disease, start lobbying governments, in order to enable allocation of funds for more research, as well as cutting edge tests and treatments.

Social perceptions of chronic illness would benefit from being re-shaped to fit the needs of growing portions of affected individuals, who struggle to fulfill duties attached their social roles.

\textsuperscript{118} K Renner (1977)  
\textsuperscript{119} A Cashel (2015)  
\textsuperscript{120} P Ewick, S Silbey (1998)
It has been shown that what qualifies as a disease and what constitutes evidence for illness can be socially negotiated\textsuperscript{121}. The legal system remains reluctant to enable coordinated efforts of surveillance, public awareness projects and research, thereby trusting the medical community to be fully equipped to do what is best for patients. While doctors are some of the most trusted sources of information for lawmakers, powerful stakeholders such as insurance companies also appear to play a great role in influencing the outcome of petitions. The scattered knowledge and wide-ranging opinions make it indeed easy for the law to reject a patient petition.

A key finding, based on the patient experiences is that more critical awareness needs to be raised on policy implications for chronic illnesses, which in the case of Lyme disease boils down to giving patients the power to construct when a person is sufficiently ill to receive support, rather than doctors or interested parties, such as insurances and disability offices.

To better address the needs of chronically ill Lyme disease patients, medical law and clinical medicine would do well to move away from the rigid test-based medicine toward flexible, patient-centered care that into account symptoms and co-morbidities, thereby providing personalized care. Along with greater awareness, such an approach will likely lead to quicker diagnosis of Lyme disease, thereby avoiding a chronic illness and saving costs on both sides.

The root of negative patient experiences appears to be based on doctors’ mistaken assumptions on the impact of chronic Lyme disease. Although not explicated stated by patients, based on doctors’ behavior, it seems likely their reluctance to take patients’ need seriously is only strengthened by the lack of regulatory guidance.

In order to fill these healthcare gaps, it would seem necessary to agree on an epidemiology description on a European level,\textsuperscript{122} while also enforcing mandatory notifications and standardized testing, more so since current surveillance statistics are built on non-standardized case criteria of uncoordinated systems of data collection\textsuperscript{123}.

\textsuperscript{121} S Timmermans (2007)
\textsuperscript{122} Z Hubálek (2009)
\textsuperscript{123} R Smith (2006)
Medical specialists inform public opinion on what merits legislation and their links to pharmaceutical companies and insurances may strongly impact if and how much the law decides to regulate Lyme disease. Meanwhile, unlike other sufferers of chronic illness, Lyme disease sufferers not only go through the often described impact on self and identity through the diagnosis and possible stigma, but are also forced to take matters into own hands due to lack of support schemes. On top of that, they are regularly mislabeled either healthy, or as suffering from other illnesses. They rightfully perceived the neglect of medical providers and the law to address vital aspects of Lyme disease management, consequently attempting to influence the law by collecting signatures, holding protests and writing letters to parliament members. Since the processes involved in diagnosis and management of chronic Lyme disease are complex and poorly understood, a change in social and legal attitudes on Lyme disease will likely be slow and arduous.

One can make the point that every German citizen is one tick-bite away from falling into marginalization, ending up without proper systematic support systems in place. It remains to be seen whether the increased sociological studies of the harm of under-regulation of Lyme disease, growing scientific evidence on the dangers of tick-borne bacteria and patient movements will soon pave the way for re-consideration of the German governments' perception of chronic Lyme disease.

As for future research areas, it would be interesting to see whether chronic Lyme disease patients are discriminated when it comes to applying for disability support, in Germany compared to other chronically ill patients. Another research field that emerged through this thesis was the exploration of healthcare misogyny in the context of time lapsed until the Lyme disease diagnosis, as well as management of symptoms.

 VII. Bibliography

Adamson, E., 'Chronic diseases, locomotor activity limitation and social participation in older women: cross sectional survey of British Women's Heart and Health Study', Age and Ageing, 33, 2004, p. 293-98

Almoussa, M., 'Stroke as an Unusual First Presentation of Lyme Disease', Case Reports in Neurological Medicine, Volume 2015, Article ID 389081


Asher, T., 'Unprecedented Antitrust Investigation into the Lyme Disease Treatment Guidelines Development Process', Gonzaga University School of Law, 2011

Ballstaedt, S., Mandl E. et al, Texte Verstehen, Urban & Schwarzenberg, 1981

Banakar, R., Theory and Method in Socio-Legal Research, Bloomsbury, 2005, p.16

Barnes, C., and M. Oliver, Disability: A Sociological Phenomenon, Ignored by Sociologists, 1993


Bean, C., Beating Lyme, Amacom, 2008

Becker, H., Outsiders - Defining Deviance, Free Press, 1963


Bologh, R., 'Grounding the alienation of self and body: a critical, phenomenological analysis of the patient in western medicine', Department of Sociology and Anthropology, St John's University, New York Sociology of Health & Illness (Impact Factor: 1.88). 06/2008; 3(2): p.188 - 206


Bradby, H., Medical Sociology, Sage, 2009


Cameron, D., 'Proof that Chronic Lyme Disease Exists', Interdiscip Perspect Infect Diseases, 2010


Cavanagh, S., 'Content analysis: concepts, methods and applications', Nurse Researcher, 4(3), 1997, 5-16

R Chenail, 'How to Conduct Clinical Qualitative Research on the Patient's Experience', The Qualitative Report Volume 16 Number 4 July 2011, p. 1173-1190


Cockerham, W., 'Medical Sociology', Routledge, 2015, p. 191


Dresscher, N., *Health as a Social Problem*, University of Aruba, 2004


Halliday S, Morgan B, *I fought the law and the law won? Legal Consciousness and
the Critical Imagination’, 66 Current Legal Probs, 2013


Inglehart, R., 'Postmodernization, Authority and Democracy', Harvard Kennedy School, 1997


Lo, B., and M.J.Field, 'Conflict of interest in Medical Research, Education and Practice', National Academies Press (US), 2009


Dr MacDonald, A.B., 'Spirochetal cyst forms in neurodegenerative disorders', Elsevier 2006, 67(4):819-32


Mehring, S., 'First Do no harm: medical Ethics in International Humanitarian Law', 2015, p.310, Martinus Nijhoff Publishing

Metcalf, N., and L Dean, Thirteen UK Lyme Disease Patient Case Studies, 2016

Metzi, J., 'Structural Competency: Theorizing a new medical engagement', Elsevier Social Science and Medicine, Volume 103, February 2014, p.126-133

Miles, M., and A Huberman, 'Qualitative Data Analysis: An Expanded Sourcebook', 1994, SAGE

Morall, P., 'Sociology and Nursing', Psychology Press, 2011, pg.75


Parsons, T., 'The Social System', New York Free Press, 1951, pg. 428


Quadano, J., 'One nation uninsured', Oxford University Press, 2005


Rizzoli, A., 'Lyme Borreliosis in Europe', Eurosurveillance, Volume 16, Issue 27,


Stricker, R., 'Lyme Disease: Call for a “Manhattan Project” to Combat the Epidemic', Pathogens Journal, 2014, 10(1) 2014

Tesch, R., 'Qualitative research: Analysis types and software tools', Bristol, PA: Falmer, 1990

Thomas, C., 'Theorising disability and chronic illness', Social Theory & Health Journal, 2012, 10, 209–228


Tuttle, C., Letter to the editor NEJM, Differentiation of Reinfection from Relapse in Recurrent Lyme Disease, 2014


Watson, A., 'Society and Legal Change', British Journal of Law and Society, 1979


Zhang, X., 'Economic Impact of Lyme Disease', Centre for Disease Control, Emerging Infectious Diseases, 2006, Vol 12 No 4.


Austrian Petition to Health Minister Alois Stoger (2016)

www.lymedisease.org

Communication from the Commission to the European Parliament (2009)

Consolidated version of the Treaty on the Functioning of the European Union (2012)

Directive 2003/99/EC

ECD Meeting Report (2011)

ECDC Borreliosis Fact Sheet (2016)

http://www.eucalb.com/


https://www.openpetition.de/petition/blog/schutz-fuer-patienten-mit-borreliose-und-co-infektionen

American Lyme Disease Foundation


Robert Koch Institut 2013

http://forum.onlylyme-aktion.org/.

http://www.lymeneteurope.org/forum/