

# Competing Online Viewpoints and Models of Chronic Illness

<sup>1</sup>Jennifer Mankoff, <sup>2</sup>Kateryna Kuksenok, <sup>3</sup>Jennifer A. Rode, <sup>1</sup>Sara Kiesler, <sup>4</sup>Kelly Waldman

<sup>1</sup>Carnegie Mellon  
Pittsburgh, PA 15213

<sup>2</sup>University of Washington,  
Seattle, WA 98195

<sup>3</sup>Drexel University  
Philadelphia, PA 19104

<sup>4</sup>Duke University  
Durham, NC 27708

## ABSTRACT

People with chronic health problems use online resources to understand and manage their condition, but many such resources can present competing and confusing viewpoints. We surveyed and interviewed with people experiencing prolonged symptoms after a Lyme disease diagnosis. We explore how competing viewpoints in online content affect participants' understanding of their disease. Our results illustrate how chronically ill people search for information and support, and work to help others over time. Participant identity and beliefs about their illness evolved, and this led many to take on new roles, creating content and advising others who were sick. What we learned about online content creation suggests a need for designs that support this journey and engage with complex issues surrounding online health resources.

## Author Keywords

Health, Interviews, Search, Social Media, Community

## ACM Classification Keywords

H.5.3. Information interfaces and presentation (HCI): Group and Organization Interfaces. General Terms: Human Factors

## INTRODUCTION

Although many people depend on their doctors to diagnose and treat acute conditions such as a sudden high fever or a broken ankle, patients tend to take a more active role in managing chronic conditions [10]. Chronic conditions are increasingly common [1], and people with chronic conditions face ongoing, often debilitating symptoms and uncertainty about the future. Most severe chronic conditions limit one or more activities of daily living (ADLs) [38]. Some conditions go into remission and then recur; others are a constant factor in a person's life. They may require lifestyle changes and complex medication regimens. Thus, "neither clinicians nor health systems... manage chronic disease, but rather patients themselves" ([10], p. 290). In the process, patients may leverage a diverse network of people and information as they develop an internal representation of their illness [15]. They may explore books, magazines, and a host of online resources for understanding and managing their condition and for finding others like themselves (e.g., [2, 6, 31]).

Eight in ten Internet users have looked online for health

information. Many say the Internet has had a significant impact on the way they care for themselves or for others [22]. For example, online support groups can influence how people understand their illness (e.g., [4,15]). Researchers have studied online health support for many chronic conditions including cancer [16,18] hearing loss [14] chronic fatigue [4], mental health [30] and autism [7].

When people with chronic disease go online, they encounter resources that diverse individuals, groups, and organizations have created [3,33]. The web can function as a support network, a source of information, a place to compare treatment options, and a mechanism for sharing information with caregivers, family, and friends [16,21]. Despite the prevalence and promise of online health information technologies, problems exist. In particular, online information can be inaccurate, incomplete, controversial, misleading, and alarming for individuals with health questions [11, 16]. Online content can have a substantial impact on patient beliefs and actions [4,15,22]. Thus, it is important to understand how inconsistent or contradictory online information and discussion affects patients.

Our work answers this question by examining how online content affects patients' *explanatory models* [29] of their illness over time, and how this in turn affects patients online and offline actions and relationships. Even before the Internet became a major source of health information, Kleinman observed a gap between a patient's explanatory models of disease and doctors' more technical definition of it [29]. Kleinman goes on to argue that patients may evolve their own explanatory model of their illness over time. Patients' explanatory models of illness are in part social constructs, and may be developed and refined in online settings (e.g., [4, 15]). Yet the details of how understanding emerges from the use of online and offline information and discussion over time are not well understood.

We extend past work by examining how Internet resources that present competing information affect people with chronic illness. We present a study exploring how people with prolonged or recurring Lyme disease symptoms engage with conflicting information online. We describe participants' experiences of information online and how these experiences change their beliefs about Lyme disease. On the surface, patients were answering questions such as "what are my treatment options?" and their online activities included search, participation in online communities, and other things predicted by the literature. However, a deeper look shows that when standard medical information did not fit patients' experience, they moved to community-based resources, and adopted new theories and practices for

SUBMITTED TO CHI 2011

managing their illness. As a result, patients' online needs shifted over time as their online activities led to changes in identity, beliefs about their condition, actions, and relationships with others. Along the way, participants took on new roles, such as interpreter of medical information and patient activist.

This work contributes to the body of HCI research concerned with information technology and health (*e.g.*, [3,7,18,35] and with sensemaking online (*e.g.*, [33]). Our results highlight important questions for those creating online health resources. For instance, should search tools help people to find the latest scientific information or the prevailing medical consensus, or should they reveal the range of opinion and debate? We argue that any online technology that dictates a single explanatory model of a health condition may not meet the needs of patients going online. When there is no simple, single answer, online health resources must be understood and designed to address participative patient needs, even to the point of facilitating active debate and advocacy. However, technology that exposes conflicting explanatory models rather than attempting to unify them must engage with complex ethical issues, as its design may have an impact on both the debate and patient outcomes.

#### **THE CASE OF LYME DISEASE**

We studied online resources for a condition called Lyme disease that is prevalent in North America and Europe. The basic facts about the disease are not in dispute. Lyme is an infectious disease caused by spirochetal bacteria in the genus *Borrelia*, carried by ticks. It can be diagnosed using a blood test, which detects the presence of antibodies to the spirochete. It can be treated with antibiotics. Lyme symptoms sometimes imitate those of other conditions such as flu or arthritis, and this can contribute to delayed diagnosis. Untreated patients may become sicker as time passes [13]. Delayed diagnosis can lead to complex psychiatric, neurological, or cognitive symptoms [8].

As we will describe, our participants confronted not just this basic explanation of Lyme disease, but at least two other explanatory models of their disease. These are described in depth in our results section, as they are grounded in our data. Given participants' uncertainty about their future and questions about how to manage their sometimes disabling symptoms, these models offered our participants different possibilities for treatment and new ways to understand their illness.

#### **STUDY**

Our study explores the holistic process by which online and offline experiences help to define a patient's explanatory model of Lyme disease over time, and how this model in turn affects patient behavior, identity, and use of online resources. Our focus was on the impact of multiple competing online viewpoints on this process. Online coherence is comparatively absent for those seeking information about Lyme disease treatment failure, reoccurrence, or prolonged symptoms.

Although our analysis focuses on data from our interviews and surveys, our interpretation of those data is also informed by the authors' experiences with chronic illness (including Lyme disease) and conversations with physicians, researchers, and patients aligned with multiple models of Lyme disease. Additionally, we attended support group meetings, visited doctors' offices aligned with multiple models, and immersed ourselves in reading online and offline content such as medical journal articles, books, forums, blogs, and web pages generated by a variety of stakeholders about both primary explanatory models.

We began this work with a survey of Lyme patients to discover how they used health resources. We conducted interviews with a subsample of volunteer survey participants to gain more insight into their experiences.

#### **Sample**

Our goal was to include people both early and late in diagnosis, and from regions where Lyme is common as well as those where it is not. We advertised using emails to regional Lyme-related email lists (1 per USA state and a few international lists), in two popular support forums for Lyme disease, and by placing a poster in the office of a doctor who treats many individuals with Lyme disease. We obtained 150 survey participants; of those who said they were open to follow up, we recruited an interview subsample of 20 patients. For interviews, we oversampled men ( $n = 6$ ) to obtain their perspective, but otherwise the interview sample was equivalent demographically and in the length and complexity of their illness to the survey participants.

The sample is not representative of all Lyme patients. People with difficult to treat or prolonged symptoms are probably more likely than others to seek support groups and subscribe to online lists. Our participants described more illness and more problems obtaining diagnoses and treatment than would be expected when Lyme is diagnosed and treated promptly. Thus, the results that we report reflect a sample of those with comparatively difficult experiences.

#### **Procedure**

We distributed a SurveyMonkey survey with a \$50 raffle as an incentive to participate. The survey included rating scales and open-ended questions about the length of time participants had symptoms, the ease or difficulty of diagnosis, the number of doctors they had seen, and their use of online resources (social networks, general Internet resources, general health sites, Lyme-specific sites).

Our goal for the survey was to include resources that participants were likely to have used, so that survey answers would vary across participants. For this reason, we focused on popularity and the ease with which a resource could be found. In the case of health resources, we also wanted to include sites from a range of categories selected from the reviews by Sood [36], Eysenbach [17] and McManus [32]. We used Google page rank for the search "lyme disease" and popularity in the patient community (*i.e.*, mentioned in discussion posts and blogs) to ensure that

we selected the most well known sites in each category. General health sites included Medline, PubMed, WebMD, Wikipedia, and CDC. Lyme-specific sites included CanLyme.com, ILADS.org, LymeDiseaseAssociation.org, LymeNet.org and LymeDisease.org.

We conducted the interviews by phone (in one case, Instant Messenger) in one to three sessions of 45 to 90 minutes. We paid participants \$10/hour. Participants completed a pre-interview questionnaire to list the online and offline resources they depended on for support and information. We asked participants about their experience with their disease and their health practitioners, treatment goals, and satisfaction with treatment. They were asked to describe particularly helpful or unhelpful online resources mentioned in their questionnaire, and whether they were currently seeking different online resources. Much of the interview was open ended, to explore participants' disease experiences and use of online resources in depth.

We analyzed the interview data iteratively, generally following Strauss and Corbin's method [37]. The first step entailed the second author's open coding of the transcripts for concepts that were significant in the data such as usage of health information, experience of disease, relationships with people, online interactions, and so forth. The resulting list of over 100 original codes was then grouped into themes. As a group, the authors then integrated the themes into findings by contextualizing them within our problem space of chronic illness and online information and communication. These themes and interpretations shifted as we discussed and also started comparing with other reports in the literature about other chronic conditions. We use descriptive labels to represent our interpretations of the experiences of the participants. All participants' names are fictionalized.

## RESULTS

Of 150 survey participants, 140 described their online activities; 128 provided demographic information. Of the 128, 18% were male and 82% were female; 95% were white. The median age range was 41-50 (compared with a median of about 37 years for the US population as a whole). All but five resided in the USA; five were from Canada or the UK. Half of the participants had a university degree or above.

Seventy-one (55%) of the total sample of 150 participants were unable to work due to disability. Thus, this sample was distinctly ill. The median time since participants were first symptomatic was 6-10 years, but they had only been diagnosed for a median of 1-2 years, a lag of more than 5 years between onset and diagnosis. Eighty-one percent characterized their diagnosis as complicated rather than simple. Twenty percent had self-diagnosed. Another 103 had seen an average of 7.8 doctors prior to diagnosis.

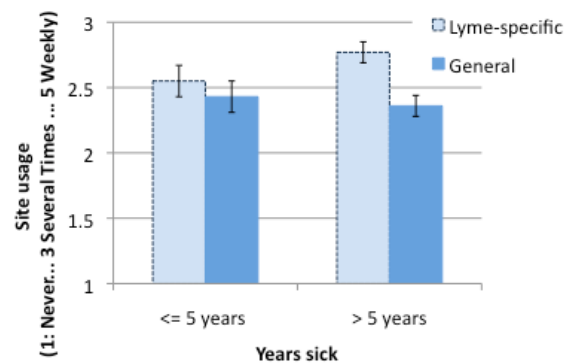
Because we were interested particularly in how the experience of being very ill interacted with online usage, we conducted mixed-models regression analyses to investigate whether participants who had been sick longer

differed in their use of online sites from those who had been sick for a shorter time. These analyses use participants as a random variable and include as control variables: gender, age, marital status, education level, and whether they used social media such as Facebook. We divided survey participants into two groups, those who had been symptomatic 5 years or less ( $n = 51$ ) versus more than 5 years ( $n = 98$ ). Overall Internet use did not differ but there was a significant difference in the frequency of use of different online resources. As shown in Figure 1, everyone visited Lyme-specific sites more often than general sites ( $F[1, 123]=11.2, p < .01$ ). Additionally, those who had been sick longer were significantly more likely to use Lyme-specific sites (students t-test,  $p < .05$ ). As we show below, the Lyme-specific sites offered a minority model of Lyme disease in contradiction to the dominant model present in general health sites.

### Explanatory Models of Lyme Disease: *Dominant, Minority, and Alternative*

We identified patients' explanatory models through an iterative process starting with bottom-up coding of interviews described earlier. Following practice for grounded theory data analysis [37], we compared our themes with (a) differing models of Lyme disease in the literature such as [39,8] and (b) other literature on explanatory models. We then iterated on them as a group. Patient stories follow a temporal trajectory, so we divided the data into starting model and ending model to understand how patients' models changed over time.

From our interviews, it became evident that our participants had encountered conflicting accounts of the disease online, particularly two prevailing explanatory models of Lyme disease. We have named them the *Dominant* and *Minority* models. We categorized less prominent models (such as those based on non-Western medicine) as *Alternative*. As noted by Kleinman [29], the models of patients and doctors



**Figure 1: Use of general health vs. Lyme-specific websites.** Darker bars show general health site usage, lighter bars (dashed outline) show Lyme-specific health site usage for people with recent onset of symptoms (5 or fewer years ago) versus those who have been symptomatic longer (more than 5 years). The general health sites were aligned with the dominant model; the Lyme-specific sites were aligned with the minority model. Regression analysis shows being sicker longer is associated with more use of Lyme-specific, minority-model sites.

were not always in alignment, and this misalignment was a force affecting participants' identities as patients. We identified these models through our analysis of participants' narratives and terminology. For example, when participants spoke of "chronic Lyme disease" and talked about long-term antibiotics and "Lyme literate" doctors, we labeled this as aligned with the minority model. Both dominant and minority models take a traditional Western medical view of the disease, but they are contradictory on several fronts, and this contradiction has led to disagreements about the diagnosis, treatment, and progression of prolonged Lyme symptoms (e.g., [23,12,19,8]). Below we describe the characteristic clusters of beliefs that we used to label which model that participant statements reflected. These statements represent world views that are presented not only by patients, but also doctors, online websites, medical articles, and so on. Going forward, we use the terms "in the minority/dominant/alternative model" as shorthand for a set of beliefs represented in our data.

*Dominant:* The dominant model is associated with the belief that Lyme disease is rare outside the USA northeast, most commonly presents with a bulls-eye rash and joint pain (although fatigue, headaches and neurological symptoms are possible [8]), can usually be diagnosed with a two-tiered blood test, and can be cured with approximately 10-28 days of antibiotic therapy, depending on how far the disease has progressed. If patients remain symptomatic, doctors are encouraged to test for other illnesses. Some patients are diagnosed with an untreatable auto-immune disorder, "post Lyme-disease syndrome" [8]. Chronic infection is not considered plausible after antibiotic therapy, although re-infection is possible. Once labeled as having post Lyme-disease syndrome, patients may still have symptoms, and treatment focuses on managing them. The Infectious Disease Society of America (IDSA), a respected organization representing infectious disease (ID) doctors who treat a range of infectious diseases, including Lyme disease, is a proponent of this viewpoint.

*Minority:* The minority model is associated with the belief that Lyme disease is common, requires clinical diagnosis because blood tests are not reliable, presents with a rash in less than 50% of cases, and may include myriad other symptoms that may easily be mistaken for chronic fatigue, fibromyalgia, depression, ALS, and many other illnesses. Lyme disease, in this view, may be frequently complicated by co-infections also carried by ticks. Antibiotic therapy may need to extend over months and treatment should continue as long as it alleviates symptoms. If a patient is untreated or inadequately treated, and symptoms persist, the infection may have become chronic, labeled "chronic Lyme disease." In the words of a doctor introducing himself in his first blog post about treating chronic Lyme disease:

*Physicians who treat this disease ... do so at their professional peril. Many Lyme advocates see this as a witch hunt against Lyme physicians. Physicians who treat chronic Lyme frequently refer to themselves as Lyme*

*literate physician, or LLMDs. They point out that hundreds of publications in well respected medical journals back up their positions with regard to the disease. I am a physician who treats hundreds of patients with Lyme disease. AT this very time the medical board in my state is investigating my treatment of patients. I have opened this blog to vent my frustrations and to perhaps help some patients who may encounter my thoughts.*

Many LLMDs base their treatment approach on repeated clinical experience with patients who did not recover when treated under the dominant paradigm. The International Lyme and Associated Diseases Society (ILADS) represents LLMDs around the world.

As described in Weintraub's book [39], the two viewpoints do not have equal standing in today's society. Insurance companies have denied coverage of treatments advocated by the minority model to patients. Researchers aligned with the minority model have difficulty publishing their work. LLMDs treating within the minority model are vulnerable in front of medical boards because they do not follow the dominant standard. As a result, many LLMD patients try to protect the identities of their doctors, a behavior we did not see mentioned by those in the dominant model.

*Alternative:* In addition to dominant and minority models, we encountered a few social and informational sites advocating mixed or other models. The many varied alternative models we encountered were generally consistent with the minority model that Lyme disease can be a persistent problem that is not easy to diagnose or treat, but advocated treatments not centered on antibiotics or Western medicine.

To estimate the overall distribution and use of online resources, we collected a random sample of Lyme disease related websites from a popular social bookmarking tool, *delicious.com*. Delicious.com has an API for downloading data about bookmarks and their tags. We collected all links tagged with Lyme from all 181 delicious.com users who were bookmarking Lyme sites over a month in the spring of 2010. The users were chosen if they used the tag "Lyme" for at least one URL. We collected thousands of URLs this way and calculated popularity by grouping URLs with the same domain name and sorted by number of users who bookmarked the URL. We coded the top 45 URLs (bookmarked by from 5 to 46 users) by author type (doctor, patient, or other) and model (dominant, mixed, or minority/alternative).

We found that 5 (11%) of these were dominant, 4 (9%) presented a mix of models, and 36 (80%) alternative or minority. Only one link was to the site of a doctor in the dominant model, and no patient-generated content was in the dominant model. To counter the clear bias toward minority sites in our *delicious.com* sample, we searched for "lyme disease treatment" on Google and selected the first 45 pages that reflected dominant or a mixture of models. When we combined these two lists, 43 (48%) were dominant, 11 (12%) were mixed, and 36 (40%) were

minority or alternative. Patients had authored 28% of the minority or alternative content, and none of the dominant content. Only 6% of minority or alternative content had been authored by doctors, whereas 14% of the dominant content had been authored by doctors. Organizations or unknown authors were responsible for the remainder. No support groups or blogs were in the dominant category. One possible reason for the alignment of patient-generated content with the non-dominant models may lie in its definition of successful treatment: A patient with chronic symptoms who accepted the dominant model would not identify as having chronic Lyme disease.

### **Participants' Changing Explanatory Models**

Encounters with content aligned with different models online influenced our interviewees' experience and identities. When they began to experience Lyme disease symptoms, ten were aligned with the dominant model, and ten with no clear model. All of the participants had become aligned with a non-dominant model (minority or alternative) by the time we spoke with them. Because so many of our participants shifted their beliefs over the course of their illness, our discussion focuses on the experiences leading to these changes.

#### *Starting from the dominant model*

Ten participants told us that at first they accepted facts associated with the dominant model of the disease and resisted contradictory viewpoints. These participants had been diagnosed in half the time (5 years on average) of other participants we spoke with. They cared about scientific evidence and current medical opinion. Jackie exemplifies this group. She is in her 40s, and is bedridden and on long-term disability. After Jackie was diagnosed, her symptoms did not disappear despite aggressive treatment in the dominant model (a few weeks of antibiotics).

*... [my doctor] explained to me about this Post-Lyme Syndrome. And he said about 10% of people have it; that made sense to me, you know, that's what he said, he was my trusted physician.*

Jackie described being very skeptical of other views of Lyme disease initially, despite having a sister with Lyme in the minority model. She found online information complex.

*... just too overwhelming, it's like, 'Oh my god, I can't look into all this, I can't do more than I'm doing.'*

Jackie's resistance to other viewpoints also derived from her wish to make decisions based on evidence and research rather than personal experience. She has a Master's degree, and spoke with great respect of support group members able to talk about current research.

*I call them 'braniacs,' ... they are scientists, they're PhD's.... And I know if I have a question ... I'm gonna get a lot of scientific information [from them], and get it answered.*

Jackie met an online acquaintance who persuaded her to think differently about her disease and treatment, but she

continued to doubt opinions in the minority model. She responded with great skepticism when online support group members suggested that her son's difficulties might be caused by congenital Lyme.

*Oh, for god's sakes ... [these people] think everything's Lyme disease. He has ADHD, you know, it's a biological thing.*

The failure of doctors to help her son eventually drove Jackie to take her son to an LLMD doctor (holding the minority model). Her son's treatment was successful, and she now speaks very positively about the minority model.

*...it's just like such an unbelievable story, and such like-a miracle, that I wouldn't believe it if I wasn't living it.*

Once these participants aligned with a new model and began treatment, their skepticism faded, and improvements in health and wellbeing were attributed to the new viewpoint, and reinforced it.

#### *Starting from rudimentary knowledge and no model*

Unlike those participants who began in the dominant model, the other half of the interview participants understood only basic facts of the disease (carried by a tick, treated with antibiotics) or had no idea they had Lyme disease. Their initial encounter with the possibility of Lyme disease was not tied to the dominant model, and when they did discover it they did not find it persuasive. Instead as their symptoms progressed, they increasingly leaned toward the minority model or an alternative. With an average of 10 years until diagnosis (double that of the other group), many of these participants were treated without success for diseases other than Lyme. Unsure what was wrong, participants hoped for improvement. They began searching in earnest for an explanation when asked to accept blame or hopelessness. Twenty years later, Kate still remembers the doctor's statement that drove her to find answers:

*'You will never be well again. You're 36 years old, you're gonna have to learn to live like this.' ... And I said, 'Absolutely not.'*

Because offline experiences caused them to initiate a search, when a person or website brought Lyme disease to the attention of these participants, they began to research it online. Thus, Kate and others like her were driven toward change initially not by what they found online, but by what they encountered offline.

### **The Influence of Online Resources**

Participants used the Internet to find research related to their symptoms. Because of the uncertainty surrounding Lyme disease, participants did not find the same answers on every site. For participants who started in the dominant model, factual sites had more weight than the opinion of other patients. For example, Alex said:

*Most of the online resources are littered with a lot of opinions and innuendo and lack of real facts. There's a lot of declarative stuff there without any reliability to it or validity.*

In contrast, participants who started with no clear model seemed less likely to trust information that did not come from other patients [cf. 35]. An undergraduate student, Jane spent two years searching for a diagnosis. She had been diagnosed a few months before she was interviewed and had just begun treatment. When she began looking at factual pages, she found that:

*It was obvious that Lyme wasn't very well understood, and I would get conflicting answers. Instead, I wanted to know what other people experienced, and I wasn't getting conflicting answers there.*

These participants put trust in patient descriptions that had similarities to their own experiences. What Jenna found in support groups swayed her to pursue the possibility of Lyme disease:

*...they had the symptoms and stuff like that listed [online] and with the symptoms I had, what they were listing they were pretty much, they were the same. Everything was the same.*

Two participants described a mutual learning process with their doctors. These doctors learned about the minority model alongside their participants. Sarah had been in treatment for only three months after being sick for more than 6 years. She described a collaborative relationship with her doctor, in which she was encouraged to bring information to the doctor and ask questions.

*...[my doctor] was so intrigued by my case, and the relief that doing this ... [has] made in my life, that she decided to go back to school and study this as her specialty.*

While participants differed in their trust of the evidence in factual sites and in patient reports, they all shared a wish for answers, and they all viewed online information as a place to find them.

#### *Interactions with online information*

Information seeking, as described by our participants, was a social process. Participants posted new sources of information or followed up on each other. For example, Jenna noted,

*...one person will write in something or another and they will have attachments with what they're writing about, and from that attachment it takes you on into another area of Lyme, and from there you gain even more knowledge about it. So it's not just a Lyme board that has people just talking about their symptoms all the time, no. They have so much information if you go on there.*

In the end, participants settled into an iterative approach to online content that increased the trustworthiness of results. Seventeen participants described a research process that included triangulation across multiple sources, including support groups.

After they settled on an explanatory model, participants started to avoid information contradictory to it. Susan describes why:

*... you know, we're going to disagree and I'm not going to change their minds by reading ... and they're not going to change my mind.*

When they settled on a model, participants did not stop using online resources altogether. Instead they engaged in more discussion with like-minded patients. Gail, whose family and friends dismissed her pain and fatigue, told us:

*...when I really feel desperate for something, you know, support, information, whatever it may be. At those times, all your life is websites.*

Eleven participants, including Gail, described meeting new people online. Jackie explained the appeal of these relationships:

*...there's such a disconnect with someone who's not sick.*

As these examples suggest, online resources not only helped participants to adopt a new explanatory model of their disease, but to adopt a new group identity aligned with others having the same or similar illness.

#### **The Explanatory Models of Other Stakeholders**

As participants began to settle on their own interpretation of their disease, they found themselves increasingly out of alignment in their offline relationships. When doctors, friends, or family opposed the minority model, participants learned to associate the model with an anti-establishment and socially undesirable belief system. Rachel reported:

*I had doctors that said you might want to look online and get in some support group [for a previously diagnosed disease] ... But then when I go to the same doctors, see them, or other specialists within the same clinic, I get truly yelled at for going online and trying to get support for the Lyme Disease.*

Some participants also discovered that questions about their belief in the minority model led to questions about whether they were really sick. Despite the severity of their symptoms, their difficulties were not always visible to or accepted by others. Gail's husband and her best friend viewed her Lyme symptoms as insignificant. Overwhelmed with emotion, she retold stories of her illness being dismissed:

*...[my husband] told me that I was crazy ...*

*...[my best friend] said, '... you know it really isn't as bad as that, because it's not like you have something that's really bad. You need to be grateful that all you have is Lyme disease and you don't have cancer.'*

Jenna was made to feel as though she had hypochondria.

*It was all in my head. I had ten noses on my face, I was making up stories.... And continual headaches all the time and you can't walk, you're paralyzed for no reason and nobody wants to take care of you. They think you're just putting on a show for them.*

By contrast, Sarah's doctor helped to support her growing understanding of her disease, and Jane's family supported her in the minority model, financially and emotionally.

*...they didn't think I was imagining things. I have a twin sister... [so] they can see that she isn't having any of the problems I'm having, so something IS wrong.*

Affirmation of this sort was a rare gift in the eyes of participants.

#### **Changing others' models**

Changing others' minds was an important part of participating in the Lyme community. Sarah, who told us how her physician had changed her specialty and practice, said,

*I guess I feel pretty proud, that I could have that influence.*

This sense of accomplishment reflects her understanding that doctors aligned with the minority model are rare. Many patients travel for hours and across state lines to find a sympathetic or knowledgeable doctor [39].

Participants were also committed to helping other patients by encouraging them to accept beliefs associated with the minority model. John told us:

*My ultimate goal, hopefully, is to try to help other people with this and tell them about ... the Marshall Protocol. It's the one thing that has worked for me the best.*

Kate describes her wish to publicize the problems she encountered:

*I said... let me start blogging about the Lyme and see if I can get any attention to it... let people know my experiences and also my treatments and ... what's going on with me and pull their attention into everything I had to go through to get any treatment at all.*

Six participants started and contributed to blogs and other online resources to provide information to other patients, friends and family. However, only two participants reported that that the information they provided led to gains in respect and understanding among their friends and family.

#### **An Active, Activist Online Community**

Participants who contributed actively to online Lyme-related content did so in the context of a distributed online patient community in which, by the time of our study (2009), the minority model had become mainstream. In Lyme forums, which mix social interaction with the interpretation of online content, participants acted out community norms, such as protecting the names of doctors and supporting other patients. For example, a sense of community responsibility drove participants to provide ongoing social and emotional support.

*...in [chat group] if someone's suicidal, we'll stay up all night with them. (Jackie)*

*...if people are asking for help. If I have information I reach out.... So it's very comforting ... and empowering to have real people out there that are trying to help that have been there. (Rachel)*

Here, Karen describes how forum members watch for hidden motives or shallow speculation about medical facts.

*... as soon as somebody says, "I tried this new thing", they'll say, "I noticed that you never posted before. Are you trying to sell us something, or what's your connection to this?" So there's ... somebody who can kind of be policing that. And even regular posters, if they post about something that's a little outside the [minority model] mainstream... they will say, 'Do you have any studies to back that up? ... why is that true for you?'*

For some participants, attempts to shield the patient community went too far. In Alex's words,

*There are webmasters who ... enforce a kind of public speak, something out of 1984... They don't like to say anything negative about the conventional [minority model] treatment ...*

Our participants' active participation in online Lyme sites also contributed to a vocal online advocacy movement. For example, participants had created or commissioned a social support site, a live group chat service, and a website that supports symptom tracking, visualization, and sharing with doctors.

Participants were also drawn into more traditional forms of activism. For example, there are state-by-state online mailing lists that provide information about local resources (e.g., nearby doctors) and support local activism such as advocating for laws increasing education or protecting physicians who treat in the minority model from censure.

Altogether twelve of the twenty interview participants described numerous small and major acts that they did to protect or advance the interests of the minority model Lyme community with which they had become aligned.

#### **DISCUSSION**

Stigmatized groups have been studied by researchers of online health resources over the last two decades (e.g., [4,30]). Outside the health domain, studies have shown how online groups can lead members to a new sense of security and self-esteem [31]. What distinguishes our study from others, we believe, is our discovery of the extent to which our participants used online resources to change their mental, behavioral, and social model of their disease.

These changes did not come overnight. One persuasive website did not make the difference. Our data shows that participants spent months to years struggling with conflicting viewpoints and engaging in discussion and information exchange with others. Many felt skeptical and experienced others' criticism, including that of their doctors and family members, before and after they adopted a new model.

As participants began to align with the minority model, they were often confronted with a disconnect between their own beliefs and those of others they related to. Although some of this conflict focused on medical fact, much of it centered around personal trustworthiness, endurance, and even sanity. Thus, a participant's explanatory model was not only socially constructed, but also profoundly affected their interactions with others (doctors, friends, family, etc.).

For members of an out-group, structural conditions such as medical protocols, payment rules, and prescription rights reinforce the in-group majority, making it hard for patients to discover or act on non-dominant models. As Sewell argues [34], the cultural schemas enacted in a complex setting, such as healthcare, “empower and constrain social action and ... tend to be reproduced by that social action.” [34, p. 91]. Thus, there is a two-way connection between structures, as expressed in cultural schemas, and personal agency, that may evolve over time.

In the case of Lyme disease, the constraints of those cultural schemas led to negative feedback and frustration that drove participants away from the dominant model of Lyme disease. Over time, participants began to take on what Castells characterizes as a “defensive identity” that can lead to the formation of a community designed to resist, and ultimately change, the current cultural norm [9]. Thus the negative feedback participants received led them to identify with a new community of people, “Lymies,” as they developed a new understanding of their disease. Defense (hiding doctors) and resistance (advocacy, activism) are defining parts of this community.

Participants worked to increase their new model’s legitimacy by engaging in activist behaviors. Their passion for this cause is reflected in a level of emotional engagement that one might not normally associate with Internet health information, as Erica’s words exemplify:

*I would risk my life to get the truth out, and to get people who are suffering from this disease ... the right kind of treatment, just information.... I feel really strongly about that.*

### **Technological and Ethical Implications**

Since this work does not provide evidence for what specific design solutions are likely to be successful, we instead focused on clarifying what questions designers may want to ask themselves, and highlighting some areas that designers may want to focus their efforts.

Many policy makers and researchers have bemoaned the presence of inconsistent, wrong, or contradictory health information online (e.g., [5,27]), including contradictory information about Lyme disease [36]. However, there is another side to this concern. It is true that patients may get misleading information or become alarmed about symptoms that are in fact not serious, or they may focus too much attention on disease processes and symptoms, leading them to ruminate about their health [6]. Alarming websites could reinforce hypochondria or cause people unnecessary concern about their health status [25]. However, attempting to resolve this uncertainty by pointing people only to dominant or accepted models belies the changing nature of medical knowledge, in which accepted models of illness are frequently overturned. It also reflects a lack of understanding about the nature of online health behavior in situations where a person’s needs are not being met.

***Expose multiple explanatory models, where they exist:*** In the many situations where knowledge of chronic disease is uncertain, people seek explanations from multiple types of online resources. We argue that, rather than causing harm, seeing the diversity of health resources online may lead to a more nuanced understanding of and involvement in the debates around a health condition. Because the scientific basis of disease, medical knowledge, treatments, and social and legal conditions for those with chronic conditions is continually changing, we argue that patients are better prepared to adjust their model of illness if they are exposed to diverse and proliferating viewpoints.

Technology could potentially help to make explicit the presence of multiple explanatory models. Researchers have begun to extract information about viewpoints in other domains (e.g., [40]). Tools that extract and visualize different health models could help patients to familiarize themselves with, and filter, the complex and divergent information currently available online.

***Help participants make informed decisions through credibility and triangulation:*** One possible way forward is technology that could also help individuals to identify more or less credible information by extracting and highlighting key features of credible sites such as those identified by Fogg [20]. Tools that help patients to keep track of, summarize, share, and rate information might also be valuable. Such a tool could be of value both to participants who are highly discerning and, as an educational tool, to those who are less knowledgeable about health information seeking.

Another option would be a search tool that facilitates a triangulation process by juxtaposing information from different kinds of resources (e.g., patient-created content and doctor-created content). If the tool included support for teaching people about the value of triangulation, it could be especially valuable to those participants who engage in less sophisticated online information seeking behaviors. It could help participants more easily learn about information they have missed or show clearly what information is more marginalized. It could also help individuals to select for information consistent with their personal model of a condition once they have settled on one.

***Acknowledge and engage with the ethics and value conflicts present in health care IT:*** There is no avoiding the ethical implications of working in this domain. Health resource designers who are cognizant of contradictory disease models need to decide how to position their practice. For instance, if a resource refers people to sites where an issue is debated or a side is taken, how are extremists to be handled? Should their comments be deleted? Should readers be warned but not protected? Who should judge who should or should not be given a voice in the debate? A design decision as simple as to give each viewpoint equivalent treatment thwarts the dominant model, gives legitimacy to the minority one, and has potentially serious legal consequences.

Although many sites focus on the debate we highlighted, there are also Lyme sites selling questionable cures. Many doctors might argue that any site not in the dominant model is selling questionable cures. What happens if a tool inadvertently highlights potentially harmful information that a patient might otherwise never have found?

Given that much American health care design work is sponsored by insurance companies, hospitals, and large health care repositories, the question of ethics in design becomes especially pertinent. Techniques such as value sensitive design [24], which explicitly address the perspectives and values of all stakeholders, could help with this process.

### Limitations

A limitation of this study is its focus on a small group of people primarily located in the US. Also, we studied only a group with prolonged Lyme symptoms. Other patients (such as those cured and those who never went online), doctors, and family members and friends, to a large or small degree, inhabit the same medical, intellectual, and cultural context. We attempted to expand our view by extensive online research of Lyme resources, as described earlier, and by talking with doctors from all sides of the controversy, but these searches and discussions do not take the place of detailed examinations of experience. A study of patients and doctors' experiences in countries where Lyme disease seems to be spreading but where models have not yet been established would be valuable for understanding how models of disease enter a culture and interact with the emergence of online resources.

This study also does not address a larger social issue surrounding patient activism. Although patient activism can be seen as a case of democracy at work, and activism may encourage positive outcomes, it also can foster extremism and uncivil debate, especially in social media (e.g., [28]). The clash of Lyme models has stimulated disrespectful commentary on each side. Here, a doctor aligned with the dominant model writes about proposed legislation that would require him to present both models to patients:

*It's a free country, and if you want to ruin your health by allowing self-serving 'Lyme specialists' and the patient advocacy groups who fail to speak for the thousands of patients who have been harmed by them to present their laughable theories about [Lyme disease], go for it. But to compel me to allow anything other than objective evidence to shape my discussion with patients referred to me for a positive Lyme serology or an ECM rash is to practice the very shoddiest form of medicine.*

As this comment indicates, there is passion and commitment in the dominant model equal to anything we found in the minority model. Our work focuses primarily on the viewpoint of people currently aligned with the minority model, and does not cover the full range of debate online or its larger social implications.

### CONCLUSIONS AND FUTURE WORK

Health researchers have learned a great deal about how people use online resources. As these sites have proliferated, health researchers have begun to turn their attention to the question of how individuals use online resources to manage their health (e.g., [2,11,15,16]). We contribute to this body of work and to the CHI community by exploring the ways in which online information and social interaction online contributes to an individual's shifting understanding of her chronic condition. Not unexpectedly, when patients are unable to resolve their Lyme disease through conventional medical treatment, they search for high quality information online. However, we also found that offline and online interactions, along with continued health problems, drove online activities that ultimately resulted in a re-constructed identity that included roles such as educator and activist in addition to illness.

An important conclusion of this paper is that any online technology that dictates a single explanatory model of a health condition may not meet the needs of patients going online. While it is relatively easy to make the case for this with a disease that is as contentious as Lyme disease, there is evidence that the conflicting explanatory models described by Kleinman [29] are the rule with chronic illness, not the exception. For example, is asthma caused by disease or is it a side effect of socio-economic inequalities? Should it be managed by (possibly expensive) medication, a change in environment, or reduced activity? Causality, management, and cure may all be viewed differently by different stakeholders and in different cultural contexts. Online tools offer the possibility of helping patients understand these competing viewpoints. Yet helping designers navigate the ethical, moral, legal and practical aspects of doing so remains a challenge for our community.

### ACKNOWLEDGMENTS

Thanks to our participants for giving their time despite the difficulties involved. Thanks to Kristin Doughty for her tutorship on anthropological research and her pointers to relevant theory during our analysis. Thanks to the reviewers for their thoughtful comments. This work was funded by NSF IIS-0916459 and Google. IRB approval #HS10-658.

### BIBLIOGRAPHY

1. Agency for Healthcare Research and Quality. (1998). *U.S. National Medical Expenditure Panel Survey*
2. Baker, L., Wagner, T. H., Singer, S., & Bundorf, M. K. (2003). Use of the Internet and e-mail for health care information: Results from a national survey. *JAMA*, **289**(18):2400-2406
3. Balka, E., Bjorn, P., Wagner, I. (2008). Steps toward a typology for health informatics. *CSCW '08*, 515-524
4. Barker, K. K. (2008). Electronic support groups, patient-consumers, and medicalization: The case of contested illness. *Journal of Health and Social Behavior* **49**(March):20-36
5. Benigeri, M., & Pluye, P. (2003). Shortcomings of health information on the Internet. *Health Promotion International*, **18**(4):381-386

6. Bessi re, K., Pressman, S., Kiesler, S., & Kraut, R. (2010). Effects of Internet use on health and depression: A longitudinal study. *Journal of Medical Internet Research*, **12**(1):e6
7. Burke, M., Kraut, R., & Williams, D. (2010). Social use of computer-mediated communication by adults on the autism spectrum. *CSCW'10*, 425-434
8. Cairns, V., & Godwin, J. (2005). Post-Lyme borreliosis syndrome: A meta-analysis of reported symptoms. *International Journal of Epidemiology*, **34**(6):1340-1345
9. Castells, M. (1997). *The Power of Identity* (Information age: V. 2). Blackwell Publishers: MA, USA
10. Clark, N. M. (2003). Management of chronic disease by patients. *Annual Review of Public Health*, **24**, 289-313
11. Cline, R. J., & Haynes, K. M. (2001). Consumer health information seeking on the Internet: The state of the art. *Health Education Research*, **16**(6):671-692
12. Connecticut Attorney General's Office. (2008). Attorney General's investigation reveals flawed lyme disease guideline process, IDSA agrees to reassess guidelines, install independent arbiter. *Press Release*. www.ct.gov. Archived by WebCite  at <http://webcitation.org/5jqlpUauz>
13. Coyle, P. (2001). Lyme disease. *Current Neurology and Neuroscience Reports*, **2**:479-487
14. Cummings, J., Sproull, L. S., & Kiesler, S. (2002). Beyond hearing: Where real-world and online support meet. *Group Dynamics: Theory, Research and Practice*, **6**(1):78-88
15. Davidson, K. P., Penebaker, J. W. (1997). Chapter 16: Virtual Narratives: Illness representations in online support groups. In K. J. Petrie & J. A. Williams, *Perceptions of Health and Illness* (pp. 463-486). Hartwood Academic Publishers
16. Eysenbach, G. (2003). The impact of the internet on cancer outcomes. *CA: American Cancer Journal for Clinicians*, **54**:356-371
17. Eysenbach, G., Powell, J., Kuss, O., & Sa, E. R. (2002). Empirical studies assessing the quality of health information for consumers on the world wide web: A systematic review. *JAMA*, **287**(20):2691-2700
18. Farnham, S., Cheng, L., Stone, L., Zaner-Godsey, M., Hibbeln, C., Syrjala, K., et al. (2002). Hutchworld: Clinical study of computer-mediated social support for cancer patients and their caregivers. *CHI'02*, pp. 375-382
19. Feder, H. M., Johnson, B. J., O'Connell, S., Shapiro, E. D., Steere, A. C., Wormser, G. P., et al. (2007). A critical appraisal of "Chronic lyme disease". *NEJM*, **357**:1422-30
20. Fogg, B. J. (2002). *Persuasive Technology: Using Computers to Change What We Think and Do*. Morgan Kaufmann
21. Fox, S., & Purcell, K. (2010). Chronic disease and the Internet <http://www.pewinternet.org/Reports/2010/ChronicDisease.aspx>
22. Fox, S. (2009). The social life of health information. [www.pewinternet.org/Reports/2009/8-The-Social-Life-of-Health-Information.aspx](http://www.pewinternet.org/Reports/2009/8-The-Social-Life-of-Health-Information.aspx)
23. France, D. (1999). Scientist at work: Allen C. Steere; Lyme expert developed big picture of tiny tick. [www.NYTimes.com](http://www.NYTimes.com). Archived by WebCite  at <http://www.webcitation.org/5jqHhP0DM>
24. Friedman, B. & Borning, A. (2002). Value sensitive design as a pattern: Examples from informed consent in web browsers and from urban simulation. In *DIAC'02*, 109-113
25. Hardy, M. S., & Calhoun, L. G. (1997). Psychological distress and the "medical student syndrome" in abnormal psychology students. *Teaching of Psychology*, **24**(3):192-193
26. Harris Interactive, cited in the New York Times. (2007). Looking for answers. [www.NYTimes.com](http://www.NYTimes.com). Archived by WebCite  at <http://www.webcitation.org/5YtGjxB24>
27. Hobson-West, P. (2003). Understanding Vaccination Resistance: Moving Beyond Risk. *Health, Risk, and Society*, **5**(3):273-283
28. Jacobs, D. Internet activism and the democratic emergency in the U.S. (2005). *ephemera*, **5**(1):68-77
29. Kleinman, A. (1989). *The illness narratives: Suffering, healing, and the human condition*. New York, NY: Basic Books
30. Kummervold, P. E., Gammon, D., Bergvik, S., Johnsen, J., Hasvold, T., & Rosenving, J. (2002). Social support in a wired world: Use of online mental health forums in Norway. *Nordic Journal of Psychiatry*, **56**:59-65
31. McKenna, K. & Bargh, J. A. (1998). Coming out in the age of the Internet: Identity "demarginalization" through virtual group participation. *Journal of Personality and Social Psych.* **75**(3):681-694
32. McManus, R. (2008). *Health 2.0 through the eyes of a diabetic - one year later*. ReadWriteWeb.com. Archived by WebCite  at <http://www.webcitation.org/5jqlzPXLq>
33. Paul, S. A. and Reddy, M. C. (2010). Understanding together: Sensemaking in collaborative information seeking. *CSCW'10*, pp. 321-330
34. Sewell, W. H. (1992). A Theory of Structure: Duality, Agency, and Transformation. *The American Journal of Sociology*, **98**(1):1-29
35. Sillence, E., Briggs, P., Fishwick, L., and Harris, P. 2004. Trust and mistrust of online health sites. *CHI '04*, pp. 663-670
36. Sood, S. K. (2002). Effective retrieval of Lyme disease information on the web. *Clinical Infectious Diseases*, **35**(4):451-464
37. Strauss, A. L., & Corbin, J. (1998). Basics of qualitative research: Techniques and procedures for developing grounded theory. Newbury Park, CA: Sage
38. Verbrugge, L. M., & Patrick, D. L. (1995). Seven chronic conditions: Their impact on U.S. adults' activity levels and use of medical services. *American Journal of Pub. Health* **85**(2):173-182
39. Weintraub, P. (2008). *Cure unknown: Inside the Lyme epidemic*. NY: St. Martin's Press.
40. Wilson, T., Hoffmann, P., Somasundaran, S., Kessler, J., Wiebe, J., Choi, Y., et al. (2005). OpinionFinder: A system for subjectivity analysis. *HLT/EMNLP'05*, Interactive Demonstrations.