

# Suffering Warriors: Uncertainty in Chronic Illness and Patients' Online Experience

## ABSTRACT

Many people go online for information and support in response to life experiences such as parenting, finding a job, and investigating an illness. Online resources may be particularly important to those with a chronic illness whose diagnosis and treatment is uncertain. This paper focuses on people with Lyme disease, the most common vector-borne illness in the U.S. today. The patient experience of Lyme disease is fraught with variability in symptoms, lack of physician experience, and uncertainty surrounding treatment and the progress of the disease. This uncertainty is reflected in an active, vocal, and contradictory presence on the web. We studied a sample of patients, finding that more difficulty in patients' real world experience predicted their more assertive use of online health resources. We describe their experiences and suggest online tools that make differing viewpoints more transparent and support an iterative search process that could help patients to manage their illness.

## Author Keywords

Health, Ethnography, Search, Social Forums

## ACM Classification Keywords

H.5.m. Information interfaces and presentation (HCI): Miscellaneous

## 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 [8]. According to data from the 1998 U.S. National Medical Expenditure Panel Survey, the number of people with chronic illness in the U.S. alone is projected to reach 171 million by the year 2030 [1]. Almost everyone encounters chronic illness directly or through a family member or close acquaintance at some point in life. Chronic illnesses, which include conditions such as HIV, diabetes, arthritis, and Lyme disease, "are prolonged, do not resolve spontaneously, and are rarely cured completely" [7]. People with chronic illness face ongoing, often debilitating symptoms and uncertainty about the future. Most severe chronic conditions limit one or more

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Figure 1: Excerpt from a website for Lyme blogging.

activities of daily living (ADLs, [35]). Some illnesses 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. Importantly, "it is neither clinicians nor health systems that manage chronic disease, but rather patients themselves" ([8], p. 290). In the process, patients may leverage a diverse network of people and information as they develop an internal representation of their illness [13], and manage their symptoms [30].

People with chronic illness can easily find a multitude of online resources for understanding and managing their illness, diagnosis and treatment and for finding others like themselves [2,28]. However, online health information can be inaccurate, incomplete, controversial, misleading, and otherwise problematic for individuals with health questions [9,16]. A national sample longitudinal study suggests that people who use health resources online experience increased depressive symptoms, possibly explained by their encountering confusing, inconsistent, and hard to verify online information and conflict in online support groups [4]. Other studies suggest more positive outcomes for some patients (e.g., [5]).

We argue here that the quality of a patient's experience with online health resources may depend on how well he or she is able to maneuver among and weigh the quality of these resources and the emotional impact of reading them. Our arguments are based on a sample survey of people with Lyme disease, and on in-depth interviews with a subsample of participants. Our contributions are (1) an exploration of

what factors predict increased online resource use, what issues cause patients to step back from online resource use, and what strategies support effective online resource use (2) the identification of a new kind of health resource use – patient activism and (3) recommendations for the design of technology that supports online health information seeking. Tools must support patients in assessing the relevance of information by presenting information about things like viewpoint, and that web services for health record management and patient-doctor communication need to support transparency and self-advocacy in the patient-doctor relationship.

## **BACKGROUND**

Our work focuses on an increasingly common and highly controversial illness, Lyme disease. There are no conclusive studies showing how to cure chronic Lyme disease. Its many symptoms are varied and changeable. They include, *e.g.*, fatigue, joint or muscle pain, headaches, rashes, and neurological symptoms [6].

Every part of the Lyme disease experience can be controversial. It is hard to describe the progression, treatment, and diagnosis of Lyme disease without taking sides in an acrid and antagonistic argument (*e.g.*, [22,10,18], and the commentary on [6]). Even the term “chronic Lyme disease” is controversial (note that throughout this paper we use the term participants universally preferred, chronic Lyme disease). Adding to the confusion, Lyme disease may easily be confused with other illnesses [43]. As a result, people with Lyme disease may face difficulties obtaining a timely diagnosis [43]. Once diagnosed, patients may have difficulty finding a doctor who believes the diagnosis, is experienced with Lyme disease and willing to treat. Untreated patients become increasingly sick as time passes [11]. This controversy affects online resources significantly – consider the history of the Wikipedia page on Lyme disease, which has at times had to be locked due to disagreements among authors. As a result, it affects people’s experience with online health resources. Additionally, there are many online resources associated with Lyme disease [41]. This combination makes Lyme disease an ideal focus for our research.

### **The role of the Internet**

Seeking health information online happens about as frequently as “paying bills online, reading blogs, or using the Internet to look up a phone number or address” [21]. The web can function as a support network, a source of information, a place to research treatment options, and a mechanism for sharing information with caregivers, family, and friends [15]. Online information can influence how people manage and treat their chronic condition [19]. According to the 2006 Pew Internet and the American Life report on online health, 86% of adult Internet users with a chronic health condition have searched for health information online [19]. Of those, about 40% take some health related action based on the information they find [19].

Many studies have explored the use of online resources by individuals with chronic conditions (*e.g.*, [25,31,46,17,12, 13]). This body of work has primarily explored how individuals use a specific resource in depth, such as support groups, or the patient-doctor relationship. Our work differs in its focus on the whole gamut of resources in use online, as well as patients’ experiences with their medical care, and how the two are related.

People with chronic illnesses have at least two important goals that online resources can serve. The first is to understand what is happening to them. There is evidence that, over time, individuals with chronic illness construct a representation of their illness [13]. Often, this representation is socially constructed based at least partly on information gathered by talking to both doctors and peers [13]. Eysenbach argues that online resources provide increased support and self education, which in turn reduce loneliness and stress [15]. Where disagreement exists about issues such as cause or treatment (as with Lyme disease), informal support networks and communities can play a strong role in helping to define what people believe about their illness, contributing to “a kind of ongoing, recursive and collective cost-benefit analysis.... What emerges is a consensual model with some flexibility to allow for individual differences” ([13], p. 481).

Another goal is self management. Self-management may include monitoring, reflection, and changes to behaviors such as diet or exercise [40]. In the case of Lyme disease, self management can be daunting. Patients may ask themselves questions such as: Do I have Lyme disease or some other disease or both? Is it possible that I am not sick or cannot be cured? Are long-term antibiotics the correct treatment? Who will pay for my treatment? Will any supplements or activities enhance my treatment? What should I tell my friends, family, and co-workers about my (invisible) condition? Even in the most supportive of environments, answering these questions is difficult. When a patient encounters antagonism or disbelief from doctors, family and acquaintances, things only get more confusing.

### **Will going online help or hurt?**

Online resources for uncertain chronic illnesses such as Lyme disease can be inconsistent, controversial, and even misleading. What are the potential risks or benefits of going online under these circumstances?

One line of prior research suggests that patients with chronic disease will gain significantly from the diversity of health resources online even if they are inconsistent and lack integration or consensus. For those seeking new information about a problem, unconnected networks can link people to knowledge that is unavailable in their existing networks such as family, friends, and doctors (*e.g.*, [32]). Accessing new, separate social environments also can have value for people who are isolated or whose existing social ties are not working well [36]. For example, compartmentalized networks were more helpful than integrated networks for single mothers establishing new role identities

through access to unique information, contacts, and role models [37]. Similarly, compartmentalized networks with family and real-world friends also enabled woman returning to college to be more adaptive (e.g., higher self-esteem, more positive moods, and fewer illness symptoms) than those with integrated networks because of the support they were able to receive from a different group of people [29].

On the other hand, an inconsistent array of resources can be confusing and increase the distress of people who are already suffering. Patients may get misleading information or become alarmed about symptoms that are in fact not serious [3]. They may focus too much attention on disease processes and symptoms, leading them to ruminate about their health [41]. Rumination increases pessimism [33] and depression symptoms [39]. Reading about disease might increase people's health anxiety, reinforce hypochondria or cause them unnecessary concern about their health status [27]. Online health websites might even lead people to purchase harmful drugs or engage in risky health practices.

Our study attempts to answer the question:

How is the real world experience of being sick, finding doctors to treat the illness, and managing one's illness related to patients' use of online resources?

## **METHODS**

Four of the authors have experience with chronic illness either from having a chronic disease or having a family member with chronic disease. One author has chronic Lyme disease, and another is a health professional whose research and clinical work both focus on patients with complex chronic diseases. We expanded our horizon by talking informally with people we had met with Lyme disease, searching the literature on Lyme disease, and documenting online resources for Lyme disease and health sites that contain information or communications relevant to Lyme disease. Based on this preliminary work, we conducted a survey of Lyme patients focused on factors that might be predictive of their online health resource usage. Following that step, the first and second authors conducted in-depth interviews with a subsample of survey participants to gain more insight into patients' experiences.

### **Sample**

We sampled 128 self-described Lyme disease patients for the survey. Our goal was to include people both early and late in diagnosis and from regions where Lyme is common and (relatively) well understood as well as regions where it is not. The online Lyme disease community is organized into regional mailing lists (1 *per* U.S. state and a few international lists). We advertised broadly using email to the regional lists. We also sampled by advertising in two popular support forums and placing ads in the office of a doctor who treats many individuals with Lyme disease. From survey participants who said they were open for follow up, we recruited an opportunity subsample of survey participants (21, or 6%) for interviewing. Except for our oversampling of men ( $n = 5$ ) to avoid bias, the interview

sample was equivalent demographically, and in the length and complexity of their illness, to the survey participants.

### **Survey procedure**

We asked participants a series of Likert scale and open ended questions about time of becoming symptomatic and being diagnosed, any difficulties with their diagnosis, and the number of doctors they had seen. We measured participants' trust in their current treating physician, adapting a subset of 10 questions from an existing trust scale [26]. We also asked participants about their gender, age, marital status, and educational level. We asked a series of open ended and scale questions about online resource use in several categories (social network use, general internet use, general health site use, time in health sites, specific Lyme site use, *etc.*). We distributed surveys using the online survey tool, *SurveyMonkey*. We offered a \$50 raffle as an incentive to participate.

### **Interview procedure**

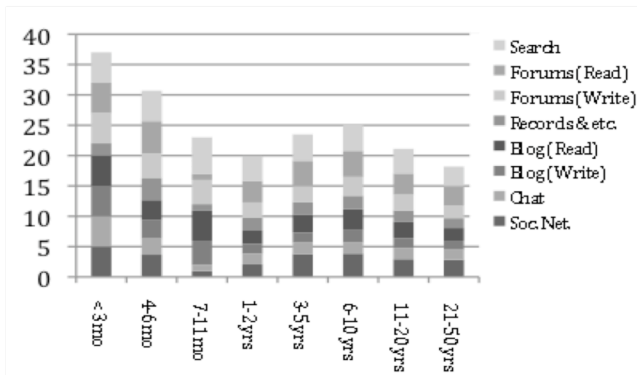
We conducted interviews by phone (in one case, Instant Messenger), in one to three sessions of forty-five minutes to ninety minutes. We paid participants \$10/hour.

Participants completed a pre-interview questionnaire to list the online and offline resources they depended on for support and information. In the interview, they were asked about their experience with their disease, and about their health practitioners, treatment goals, and satisfaction with treatment. They were asked to describe particularly helpful or unhelpful online resources (using the questionnaire as a basis), and whether they were currently seeking different types of online resources. Much of the interview was open ended, to probe and explore responses about participants' disease experiences and online resource use in more depth.

Our analysis was drawn from the bottom-up coding method used in grounded theory [24]. The first step entailed the first author's open coding of the transcripts of all of the interviews. We coded for concepts that were significant in the data such as abstract representations of usage of health information, experience of disease, relationships with people, online interactions, and so forth. The resulting list of 35 original codes was then grouped into themes ("axial coding"). The themes were then integrated into findings by contextualizing them within our problem space of chronic disease and online information and communication.

## **SURVEY RESULTS**

Twenty-three survey participants (18%) were male and 104 (81%) were female. The mean age was in the 41-50 range, with a majority of participants between 31 and 60. Most were not married, (82%) and Caucasian (95%). All but eight resided in the U.S (the remaining were from Canada or the U.K.). Half of the participants had a Bachelors degree or above. Despite their high level of education, 87% of the participants were unemployed. Many of these (62%) were unable to work due to disability. Thus, this sample was measurably ill. The median time since participants were first symptomatic was 6 years, but they had only been



**Figure 2:** The use of different types of online health resources changes as the illness progresses from 3 months or less of symptoms to 12-50 years of symptoms. Note that this view does not control for the impact of age or other factors. From top to bottom this shows search, support (reading messages), support (writing messages), health records & services, reading blogs, writing blogs, chat, and social networking.

diagnosed for a median of 4 years, a lag of 2 years between onset and diagnosis. 82% characterized their diagnosis as complicated rather than simple. On average, participants had seen 11 doctors [SD=15], although this average was increased by a long tail in the distribution (*i.e.*, outliers). Without the outliers, the mean was still 9 [SD 11].

On average, participants reported using 7 [SD=3] different Lyme specific websites and 5 [SD=1] different general health websites. We asked about frequency of use for a subset of common Lyme websites, general health websites, and for online behavior such as online social network use. Figure 2 summarizes these results grouped by the length of time an individual has been symptomatic. Search and reading blogs were the two most consistently used health activities at all stages of illness.

### How does the real world experience of being sick relate to the use of online resources?

We wanted to test whether greater uncertainty and complexity would drive participants toward the Internet to understand and manage their illness. To answer this question, we would need to control for factors such as participant age and overall Internet use. To explore these questions in a more nuanced way, a regression analysis is the appropriate tool. We ran a series of regressions to predict participants' use of online resources, as follows:

*Online health sites.* We asked participants how often they engaged in health-related activities such as participating in chat rooms and searching for health information. We averaged the scores of 8 items. The Cronbach's alpha is .85.

*Time in health sites.* We also asked participants how much time they spent in health-related activities online and averaged the scores of 5 items. The Cronbach's alpha is .73.

*Lyme sites.* We asked participants how often they visited or participated in a list of 13 sites specific to Lyme disease and averaged their scores. The Cronbach's alpha is .80.

*Medical information.* We asked participants how often they used 7 medical literature sites such as Medline. The Cronbach's alpha is .69.

The following variables were used as predictor (independent) variables in the regression analyses.

*Lyme disease experience.* We used the number of doctors seen as a measure of the complexity and uncertainty surrounding the person's Lyme disease. This number was highly skewed, and thus for analysis we used a log transformation of this variable.

The years since symptoms and since diagnosis were highly correlated so we used only one of these (time symptomatic) in our analyses. We reasoned that patients with more recent Lyme disease symptoms would use the Internet more to seek out information and advice.

*Trust in doctor.* We found one stable factor accounting for 66% of the variance, and a scale made up of these items gives a Cronbach's alpha of .94.

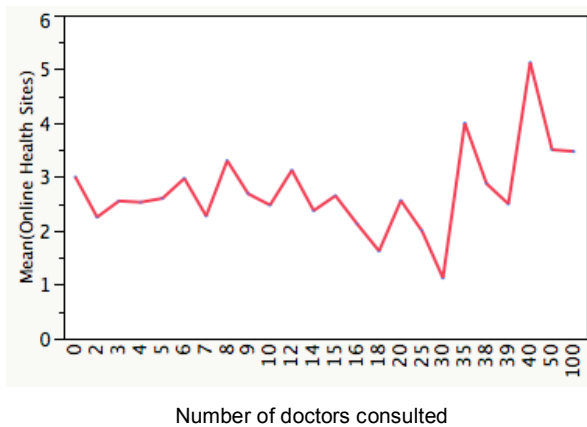
To control for people's use of the Internet more generally, we used the scales to measure their non-health social networking (use of MySpace, Facebook, Twitter; Cronbach's alpha = .67) and their use of the Internet for non-health purposes such as email (6 items, Cronbach's alpha = .75)

The results of the regressions consistently showed that the more doctors a patient consulted about his or her Lyme disease, the more he or she used Internet health sites (see Figure 3). Thus, the number of doctors seen predicted the frequency with which participants used online health sites ( $F [1, 87] = 5.4, p = .02$ ). Another significant predictor was the trust in doctor scale: more trust led people to visit online resources more ( $F [1, 87] = 3.9, p = .05$ ). This contradicted our intuition that *distrust* of one's doctor that would drive people to use the Internet. There was trend showing that having the illness a shorter time predicted more use of the online health sites ( $p = .11$ ). Finally, as expected, more overall use of the Internet was a strong predictor of using online health sites ( $F [1, 87] = 12.9, p < .001$ ).

The results for time spent in online sites were similar, with the number of doctors consulted predicting this time ( $F [1, 87] = 3.7, p = .05$ ), the trust in doctor scale positively predicting time spent ( $F [1, 87] = 4.6, p = .03$ ), and a shorter time since first symptoms also predicting but marginally ( $F [1, 87] = 3.1, p = .08$ ). Overall online communication also predicted spending more time on the health sites ( $F [1, 87] = 3.7, p = .05$ ).

Results for the average frequency of visiting one or more Lyme-specific sites showed that the number of doctors marginally predicted these visits at ( $F [1, 87] = 3.5, p = .06$ ). The trust in doctor scale did not predict, but age, one of the demographic variables did. Older participants used these sites more ( $F [1, 87] = 3.7, p = .05$ ).

In summary, having a complicated case, as evidenced by the number of doctors seen, is predictive of online activity including the number of sites visited and the time spent



**Figure 3.** Relationship of the number of doctors consulted and patients usage of online health sites.

online. Surprisingly, trust in one's doctors also predicted online activity. It is possible that more information is leading to more trust in the doctor, or to finding more trustworthy doctors, or that a trusted doctor is encouraging a positive online experience. Our survey is cross-sectional and thus cannot show causality, which is why we turn to the interviews for a better understanding of our data.

### INTERVIEW RESULTS

In the first phase of the interview, we asked participants to tell us their story. These stories were hugely varied and often heartbreaking. In almost all cases, the protagonist found himself or herself wandering through a netherworld of strange diagnoses and unhelpful treatments.

#### What's wrong with me?

Unwilling to believe in an illness without reason, or encouraged by a friend or family member to consider Lyme disease, the participant began searching, usually online (12 interview participants).

Rachel (names have been changed to pseudonyms to protect anonymity), who went undiagnosed for over 6 years, describes how a combination of support group posts and scientific articles helped convince her to investigate more:

It was on one of the support sites ... [someone] said you need to get tested ... [by a] certain lab... you know, the tests are inaccurate that you've had... [this was confirmed by] information that was not from people, patients. It was from, you know, scientists and microbiologists and doctors... And that's when I thought I can't trust to be treated right... I'm going to have to, you know, go get some answers. (Rachel)

Jane went undiagnosed for about two years. She was suspicious of a doctor who was medicating her constant pain without a diagnosis, but was wary of becoming an "Internet hypochondriac, so at first, I completely ignored any suggestions of things like [Lyme disease]." Eventually, she decided to investigate and "quickly found ILADS [International Lyme and Associated Diseases Society] list of symptoms, and I had probably 75% of them."

Jane described reading competing research studies of Lyme disease, discovering that one key organization had been prosecuted over financial ties that might have influenced its restrictive and influential statements about Lyme disease,

and that "The CDC seemed to be ignoring very clear evidence about Lyme disease." She concluded:

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... I found people who had symptoms exactly like mine (Jane).

All of the participants we spoke with were eventually diagnosed, and either in treatment, unable to afford treatment, or in remission. Some were still actively expanding their understanding (Rachel: "I'm trying to get a hold of the history of Lyme and how we got to where we are now"). Others reached a phase where they were not actively searching for resources and were just, as Susan says, "keep[ing] an ear to the ground" in sites that had already proven to be effective sources of information. Some stepped back a bit (Jane: "I don't want my life to start revolving around Lyme disease, and these websites, so I've stopped actively looking for more, now that ... I've found websites that offer support"; Gail: "...it's just overwhelming to me sometimes, to just go in there and read all that stuff."). Others became more active in the larger Lyme disease community (Erica: "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.").

#### A diversity of resources

The resources our participants used included interpersonal email, community resources (support groups, live group chat, and mailing lists), content (research articles, organizational websites, medical portals, Wikipedia, *etc.*), blogs (read and/or written by participants), symptom tracking applications, and medical record sites.

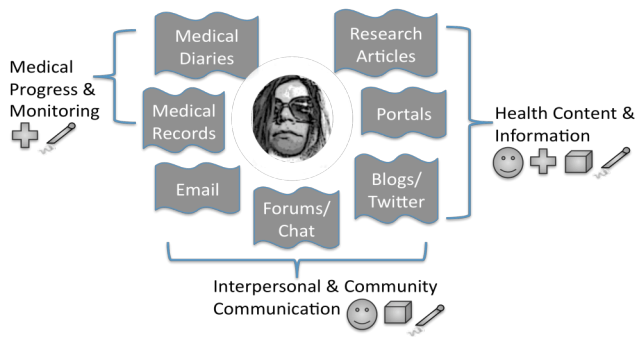
This list includes every category mentioned in the reviews by Eysenbach [15] and McManus [38] except e-commerce (which is not something we explicitly asked about) and advanced Health 2.0 technologies that do not yet exist in the Lyme community. Additionally, Eysenbach and McManus did not discuss the use of technologies such as live group chat for health.

As illustrated in Figure 4, doctors, organizations, and individuals with Lyme disease all participated in the creation and consumption of this varied set of content. Here we give some examples in each category.

#### Medical progress and monitoring

Eight interview participants kept track of their symptoms, medical tests, medication taken, or other important resources or ideas. Their reasons for doing this included suggestion of a health care practitioner or another patient, difficulty remembering due to cognitive impairments caused by their illness, distrust of doctors, or difficulty making sense of a highly variable illness.

Like for 3 days, I'd feel really okay, and then for 2 days I'd feel horrible. And I couldn't make sense of that... So I was marking on the calendar, like, you know, giving each day a



**Figure 4:** Types of resources used. Different resources are used to communicate with or receive communication from a variety of sources including: + doctors; [document icon] organizations; [smiley face icon] other people (including strangers, close friends and family, and the individual's extended social network). We show [pencil icon] where patients are creating content themselves as opposed to simply consuming it.

number of how I felt, and trying to see if the good days were increasing... (Jackie)

Patients tracked symptoms, sometimes daily (“I can look back and be like, “oh my god, I had like a whole week of 10’s! I did feel really good then” – Jackie, and four others), medication, other medical events, such as diagnoses, test results, and doctor’s visits (“with my granny-sized pillbox, I can look at [my chart] and be like, ‘oh, I need to take the morning pills for Monday’” – Susan, and 2 others), and used writing to process a difficult experience (“it helps sometimes to write stuff down, just to write your thoughts down” – Mary, and 2 others), and to help with faulty memory (“And I’m doing it, as I said, just to one, document, because I don’t remember. I honest to God don’t remember everything that happened to me.... So I document as I go.” – Kate). The frequency and quantity of information recorded both tended to go down over time, although some participants kept recording symptoms and other medical details for years.

Although personal record keeping helped participants, charting symptoms can also be problematic, as described by Mary, who later burned everything she had written down:

Because one of the things I’ve learned is the more you concentrate on the symptoms, the more symptoms you’re gonna get. (Mary).

Participants usually stored information on personal computers or paper. For example, two participants tracked their symptoms using LymeLog, a social online tool for symptom tracking. LymeLog currently has a community of over 600 users [33]. Jackie reported that acquaintances shared the results of symptom tracking with a doctor, but none reported doing this themselves. Only one participant, Jane, reported that her doctor had encouraged her to track her symptoms.

#### *Interpersonal and community communication*

All participants communicated with family and friends, their wider social network, and anonymous strangers through email, forums, chats, and blogs:

- Some participants (3) introduced online resources into their immediate social networks (friends, family, and coworkers):

every time I talked to a different family member or friend, I had to answer all of the same questions over and over again so I started [a] blog... (Susan)

- Others (11) met new people:
  - ... so I have a whole new set of friends... that also happen to have Lyme disease ... And I don’t have to- like, there’s such a disconnect with someone who’s not sick... (Jackie)
- Many (15) used online resources to ask and answer questions, to get news about new treatments, to get reviews of doctors, or to get support.

The presence of conflict online impacted the success of these activities. For example, Susan avoided certain resources because “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.” Jackie, who helped to moderate a social site, described the difficulty of getting members to talk nicely about alternative vs. allopathic treatment approaches, saying “we’ve accomplished a lot in getting these two sides to be working together, like for the first time ever in years....”

As mentioned earlier, some participants reached a phase where they used online resources less because the amount of information was overwhelming. Participants avoided certain resources for similar reasons – “it doesn’t take long to know if it’s a good place or not for your well-being.” (Mary).

#### *Health content and information*

All participants searched for and read online health-related content. Controversy affected this process, as described by Lisa: “It’s kind of hard to wade through all of the information and find out what is an appropriate choice for my own treatment, when there’s so much controversy.” Participants reacted to this by developing a strikingly sophisticated understanding of how to vet online resources. As Jen says, “You just can’t start reading any old thing and think that this is what it’s all about.... You’ve got to read anything and everything and in doing that ... you know which one is telling you the truth.” Sixteen other participants described a research process that included selecting among different types of information and/or triangulating sources. Jen again:

before I click on anything I read the bottom portion of it as to where it is coming from. If it’s from a medical school, a medical background, a doctor, or of that nature, that is the ones I will pick to read. I won’t just pick something that, you know, some Joe Blow that I’ve never heard of to read it. It’s got to be something that I have heard about, heard from. I just don’t pick any old thing to read (Jen).

Five participants mentioned concern about possibly scams. Scam awareness and discerning information consumption were actively taught and monitored in support group settings. For example, Karen described how a forum she is on was publically moderated:

... 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 mainstream... they will say, "Do you have any studies to back that up? Why would you think-- why is that true for you?" (Karen)

More generally, information seeking, as described by our participants, was a social, often iterative process. Forums helped eleven participants to find multiple sources and vet the trustworthiness of information they found. Discussion participants posted new sources of information and talked about them. Some followed up on pointers from online groups and/or read sources directly:

...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 (Jen)

In summary, participants used online resources in different ways at all phases of their illness. Because of the uncertainty surrounding Lyme disease, they did not find answers on a single site. Despite chronic pain and, in some cases, cognitive difficulties, many approached online information with sophistication. Discriminating, critical readers, they perused research articles and attempted to gather information from diverse and reputable sources. In the process, participants became experts in their own disease.

After the first jolt of information, participants did not stop using online resources, but they did use them for more specific reasons. Sometimes their goals were practical, involving ongoing disease management, support, tracking new research results, while at other times:

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

### **The manager role**

As already described, participants used and produced information in the course of communicating with strangers, doctors, friend and family. But it is important to step back and understand the degree to which these activities fed into the task of self-management.

Participants faced several complex problems. As already described, simply keeping track of 40 or more symptoms can be a daunting task requiring explicit tracking. Similarly, we have already described the ways in which participants managed their extended network (*e.g.*, creating a blog to avoid answering the same questions over and over again). Participants also had to manage their doctors. As described in our survey results, the average participant had seen 9 doctors [SD 11]. These doctors typically did not communicate much with each other, and often each one had

a myopic view of the participant's illness. The result is that participants depended less on their doctors and more on themselves and trusted sources online:

you don't get a connection with these doctors at all. They look at you. They, kind of, patch you up. They send you home with a bunch of drugs and you'll go home and deal with it. So I - it's just not - it's not a mistrust in all doctors. It's just that there's not much connection (Rachel)

For participants who did not have financial or geographical access to a doctor with experience treating Lyme disease, there was no one to coordinate among these diverse physicians except the participant him- or herself. Some of the things participants attempted to coordinate included information about medical history, tests that had been done, symptoms, and possible new treatments. Because their cases were more complicated as a whole than the pieces each specialist seemed to address, participants were driven online to research the choices their doctors were making.

Doctors did not always react well to this. For example, Emma and Sarah both described being discouraged from investigating their illnesses by a previous doctor. In Sarah's words: "I said I had done some reading ... he told me I was a 'textbook idiot.'" However some doctors supported and even encouraged patient research, as with Sarah's new doctor. Sarah photocopied or printed articles for her doctor and developed theories which she would ask her doctor about. "She read that bit of information, did some research of her own, got back to me...." Five other participants also described doctors supportive of online research, which may explain the phenomenon found in our survey where patients went online more when they trusted their doctor.

I've been able to bring papers ... He's very open to them... usually he's got 20-30 minutes to spend with you. But he'll talk if it's interesting. I brought him a couple articles. (John)

### **The warrior role**

While many of the ways in which our participants used online content reflected known practices, there were some important discrepancies that were driven by the conflicts associated with Lyme disease.

#### *Fighting for health*

Many participants described a continual battle for compassionate and effective treatment. Online resources helped them with this. For example, Rachel described using her HMO's online system to view her blood test results, saying "And I really learned to take advantage of that to protect myself, mainly...." She went on to describe a case where "...they've told me that things were normal. But then, when I look at the results, they're not..." Similarly, John, Kate, and Erica kept track of their symptoms to help substantiate the symptoms they were experiencing in the eyes of the doctors (John: when you first get this thing you're very obsessed, because you're really sick and you've been to plus 10 doctors and they've all said, "There's

nothing wrong with you. It's a psychiatric issue.”; Kate: “I... almost had them convince me that I was crazy”).

#### *Fighting for respect*

Participants faced disbelief and other negative reactions among everyone from close family members (spouses, children, *etc.*) to extended family and friends to doctors. Some were misinformed, while others actively opposed or disbelieved the participant's illness. Of the thirteen participants who were misunderstood or disbelieved by those in their immediate social network, two (Susan and Sarah) used an electronic diary to provide details of their personal experiences and educational information. Both of these participants, along with two others, said that the information they provided led to gains in respect and understanding among their friends and family.

#### *Fighting for the community*

The Lyme community is characterized by people who have stepped into unexpected activism, from the journalist who wrote a careful social/political history of the disease [43] to the lawyer who brought the Infectious Disease Society of America to court for writing biased guidelines [10]. A vocal self-advocacy culture has developed among those suffering from Lyme disease. It is characterized by an organized and active presence online, in part because it is hard to find in-person support groups in most cities. For example, State-by-State mailing lists provide information about local resources (*e.g.*, nearby doctors) and support local activism.

Activism is a constant and integral part of the experience being part of the Lyme community. As illustration of this, in the course of recruiting participants, we were asked about financial or intellectual ties to distrusted organizations, and our own qualifications and intentions. Interviewees were also extremely cautious about sharing names of doctors with us, us, in most cases referring to people using abbreviations. They were following a rule in place in almost every online Lyme community. This unwillingness to share doctors' names is a form of protection – numerous doctors who specialize in treating chronic Lyme disease have faced the possibility of losing their licenses [43], thanks to the disagreements about treatment in the medical community.

A notable trend is the creation of resources as needed to overcome various gaps in online support. For example, one participant and her husband created a new social support site when the one they were using turned out to be a scam. They also created a new live group chat service to replace a previous one with older technology. This same participant describes how her needs led to the creation of LymeLog, a Lyme specific website that supports symptom tracking, visualization, and sharing with doctors:

It actually was developed by a friend of mine because I used to just write like a diary, like in a Word document every day... and I had shown it to him, and he's a computer programmer, and he said, 'oh, I could make this into something really easy for you,'... So for a couple of months, I kept telling him, 'you should make

this public, I mean this is *amazing!* Let other people use this.' So he finally did. (Jackie)

In sum, twelve participants described numerous small and major acts that they did to protect or advance the interests of the Lyme community. Each person brought his or her own skills to the table. For example, Sarah moderated a mailing list. Jackie described a sub group of people that “do 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, and get it answered.” Kate kept an online diary detailing symptoms and treatments to explicitly publicize her experiences:

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. (Kate)

Rachel answered questions “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.” Jackie provided support “...in LymeChat if someone's suicidal, we'll stay up all night with them.”

#### **DISCUSSION**

Our participants' experiences with their illness and their search for a cure and a better life are implicated heavily in their use of Internet health resources. Consistent with the literature, our participants depend on and benefit from access to knowledge and support from networks of people and information to which they were previously unconnected. Despite the presence of contradictory and uncertain online information about Lyme disease, participants said that their access to this information helped them to find a diagnosis, manage their disease, and ultimately contribute back to the community. At the same time, also consistent with the literature, patients at times reported a negative psychological impact that caused them to step back from online information.

Why did participants go online? They described going online when it would benefit them or others. In this vein, one driving factor was needs, including both emotional and instrumental needs that were not being met. Another factor was the complexity of their health situation, as suggested by the results of the survey showing that having many doctors predicted a higher frequency and longer time in online health sites. Trusting one's current treating physician was also predictive of using online health resources. The interviews suggested different causal explanations of this finding. Almost half of the patients said that online resources helped them find a trusted doctor. Others said a trusted doctor encouraged them to use online resources. Finally, the needs of others drove online activity such as educating the general public, helping other patients, and other forms of activism.

A limitation of our study is its focus on a single disease. We implicitly compare our sample to those with acute Lyme



and those with other, perhaps less contentious, diseases. Future studies will compare samples like this one to other groups.

### DESIGN RECOMMENDATIONS

Technology can support patients without dictating their actions. First, a search tool could facilitate the “triangulation” process described by numerous participants by juxtaposing information from different kinds of resources. If it included support for teaching people about the value of triangulation, this tool could be especially valuable to those participants who are less sophisticated.

Second, researchers have begun to extract information about viewpoints in other domains [44,45]. Tools that extract and visualize viewpoints could help patients familiarize themselves with, and filter, the complex and divergent information currently available online. Such tools could help participants more easily learn about information they have missed or accidentally ruled out.

Third, technology could help individuals identify more or less credible information by extracting and highlighting key features of credible sites such as those identified by Fogg [19]. 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.

In addition to these tools, technology could engage with the managerial, social, and advocacy (warrior) aspects of the patient experience. For example, tools that help patients to keep track of, summarize, share, and rate information might be valuable additions to current tools and forums.

Although information exchange often takes place in the public sphere, similar tools for the private and personal sphere have value. A tool that supports patients in managing multiple doctors is a difficult challenge that is already being tackled by organizations such as Microsoft HealthVault. Our data highlight the fact that such a tool would need to give patients a voice and support transparency, including views of their own data and of what their doctors are considering, along with the risks and tradeoffs of following different possible diagnoses or treatment plans.

### 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., [15,13]). We contribute to this body of work and to the CHI community by exploring the interaction between a person’s own medical history, experience of illness, and interpersonal support structure, and their online resource use. Our results suggest that when real-world circumstances force patients to fight for their health, they search widely for high quality information but also protect themselves from negative emotional influences, even to the extent of limiting online

activity that seems counter productive. Yet there are times when online resources are a patient’s only resort and only outlet. Our results point a rich set of possibilities for the design of tools that support individuals when they are faced with the need to go online for health reasons.

### ACKNOWLEDGMENTS

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