
Uncertainty in Chronic Illness and Patients' Online Experiences

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Abstract

Many people go online for information and support in response to life experiences such as parenting or 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 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 interviewed 21 patients about their real world and online health-related experiences. Here we discuss the strategies that support effective online resource use. An unexpectedly prevalent form of online activity was patient activism.

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 broken ankle, patients

tend to take a more active role in managing chronic conditions [5]. Almost everyone eventually encounters chronic illness directly or indirectly. People with chronic illness face ongoing, often debilitating symptoms and uncertainty about the future. Importantly, “it is neither clinicians nor health systems that manage chronic disease, but rather patients themselves” ([5], p. 290).

Seeking health information online happens frequently, and online information can influence how people manage and treat their chronic condition [8]. The web can provide support, information, a place to research treatment options, and a mechanism for sharing information with others [6].

Online health information can be inaccurate, incomplete, controversial, and otherwise problematic for individuals with health questions [7]. Perhaps because of this, people who use health resources online may experience increased depressive symptoms [2]. Misleading information may lead them to take harmful actions or become alarmed about symptoms that are in fact not serious. Reading about disease might increase people’s health anxiety, reinforce hypochondria or cause them unnecessary concern about their health status [10].

Other studies suggest more positive outcomes for some patients (*e.g.*, [2]). 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.*, [11]). Accessing new social environments can have value for people who are isolated or have ill-functioning existing social ties [12].

Our work focuses on an increasingly common and highly controversial illness, Lyme disease. Lyme’s varied and changeable symptoms include, *e.g.*, fatigue, joint or muscle pain, headaches, rashes, and neurological symptoms [4]. There are no conclusive studies showing how to cure chronic Lyme disease, and there is disagreement in the medical community about its diagnosis, progression and treatment (*e.g.*, [9], and the commentary on [4]). As a result, people with Lyme disease may face difficulties obtaining a timely diagnosis [13]. Once diagnosed, patients may have difficulty finding a doctor or getting insurance companies to pay for treatment [13]. This controversy significantly affects online resources and people’s experience with online health resources.

Study

Four of the authors have personal or professional experience with chronic illness, including chronic Lyme disease. 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 we conducted in-depth interviews with 21 people with Lyme Disease to gain more insight into patients’ experiences.

We conducted interviews by phone (in one case, Instant Messenger), in one to three sessions of forty-five minutes to ninety minutes. We advertised for participants online and placed ads in the office of a Lyme specialist. Participants completed a pre-interview questionnaire listing the online and offline resources they use. In the interview, they were

asked about their experience with their disease, health practitioners, treatment, and particularly helpful or unhelpful online resources. Much of the interview was open ended. Payment was \$10/hour.

We used a bottom-up coding method drawn from grounded theory. One author conducted open coding of the interview transcripts for concepts that were significant in the data such as abstract representations of usage of health information, experience of disease, relationships with people and online interactions. The resulting list of 35 codes was then grouped into themes ("axial coding"). The themes were integrated into findings by contextualizing them within our problem space of chronic disease and online information and communication.

Interview Results

All of the participants we spoke with were diagnosed, and either in treatment, unable to afford treatment, or in remission. Five participants were male, most were single. The mean age was 41-50. Over 80% were unemployed, about 60% of these due to disability. Over 80% characterized their diagnosis as complex, and the mean time from symptom onset to diagnosis was two years.

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. Information seeking was described as a social, often iterative process. Forums helped eleven participants to find information.

The presence of conflict online impacted this process. 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."** Lisa visited many resources because: **"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 developed 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 any-thing and everything and in doing that ... you know which one is telling you the truth..."** Sixteen participants described a research process that included selecting among different types of information and/or triangulating sources. Participants described how forums helped them to vet the trustworthiness of information they found, and avoid scams. Scam awareness and discerning information consumption were actively taught and monitored in support group settings.

Participants used online resources at specific times for specific reasons including ongoing disease management, support, and tracking new research results: **"...when I really feel desperate for something, you know, support, information, whatever it may be. At those times, all your life is websites. (Gail)"** At the same time, participants actively managed the negative side of going online by reducing some online activities.

Although not predicted by past work, the pull toward activism was strong among participants (12 of 21).

“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. (Erica)” Participants described numerous acts that protected or advanced 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 **“see if I can get any attention to it... and pull their attention into everything I had to go through to get any treatment at all.”** Rachel answered questions **“If I have information I reach out.... 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.”**

Conclusions

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. Participants actively managed the negative impacts of going online mentioned in the literature. Overall, 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.

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