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

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What is this talk about?

- Ethnographic study of chronic illness patients about how they used online resources

- Human-computer interaction research
- User-centered design
  1. Study potential users through surveys, interviews, observation, and so on
  2. Formulate design recommendations
  3. Create novel technology!

Talk Outline

- Introduction
- Methods
- Results
- Design Recommendations
- Future Work

Chronic Illness and the Internet

- Many people in the U.S. have one or more chronic illnesses
  - Projected to reach **171 million** by 2030 (1998 U.S. National Medical Expenditure Panel Survey)

- Chronic illness patients take a more active role in management
  - *Clark, N. M. , Management of chronic disease by patients. Annual Review of Public Health, 2003*

Chronic Illness and the Internet

- There is a multitude of online resources useful for chronic illness patients:
  - Understanding the illness
    - Progression
    - Diagnosis
  - Managing the illness
    - Treatment
    - Symptoms
  - Finding others that have a similar experience
- *(Baker, L., Wagner, T. H., Singer, S., & Bundorf, M. K., Journal of the American Medical Association, 2003; Harris Interactive, cited in the New York Times, 2007)*

Chronic Illness and the Internet

- However, these resources can have problems.
- They can be:
    - inaccurate
    - incomplete
    - controversial
    - misleading
    - …and so on
- *(Cline, R. J., & Haynes, K. M., 2001; Eysenbach, G., Powell, J., Kuss, O., & Sa, E. R. 2002)*

What can be done to help?

- Controlling what health information is available
  - Automating assessment of the accuracy of online health information
  - Developing and enforcing standards
- Encouraging discerning readership in patients
- *Anything else?*

So do online resources help or hurt?

- Increased depressive symptoms as a result of
  - Problems with online health information
  - Conflict in online support groups
  - *Bessier, K., Pressman, S., Kiesler, S., & Kraut, R. ,2009*
- Increased feeling of self-efficacy and control
  - *Broom, A.Qualitative Health Research, 2005*

Consider a Chronic Illness that:

- Has no conclusive studies showing how it may be cured
- Has many different types of symptoms
- May easily be confused with other illnesses
- Has highly varied and complex progression, diagnosis, and treatment…
- … all of which are fraught with disagreement and controversy among medical professionals

Consider Chronic Lyme Disease

- Symptoms include fatigue, joint or muscle pain, headaches, rashes, and neurological symptoms
- Difficulty getting tested and diagnosed
- Difficulty finding a doctor who believes the diagnosis, is experienced with Lyme disease, and is willing to treat
- Even the term "chronic Lyme disease" is controversial

An Online Voice

- There are many resources focused on Lyme disease:
  - A multitude of websites aimed to provide information on prevention, diagnosis, and treatment
  - A strong online community, active on discussion boards, blogs, social networking sites, mailing lists, and so on

Earn 10 credits by attending the ILADS professional conference. Get updated information about the ILADS Conference on October 24-25, 2009 by signing up below.

Enter your name and email address and we'll keep you updated about the conference.

Be part of the solution!

ILADS Lyme Disease Conference

Over 40 different workshops, keynotes, plenary sessions, and roundtables.

7 hours of programming

Welcome to LymeBlog

Your place on the web for News Articles and Personal Stories (Blogs) About Lyme Disease in the World

View All LymeBlogs

Scroll down or click here for the latest news stories from throughout the world

"... the depth of ignorance is staggering."
Alasdair Crockett (1968-2006)

BIG NEWS! Over 1000 blogs on LymeBlog
Congratulations to elr1227 for posting the 1000th blog on LymeBlog

YOU ARE NOT ALONE
Tell Your Story
Start your own Lyme Web Log (LymeBlog)
If you have Lyme or are close to someone who does
Click Here to start a free LymeBlog journal

Help fight the ignorance
Share your story

The Study

- The population: chronic Lyme disease patients
- The technology: online health resources
- Topics explored:
  - What factors predict increased online resource use?
  - What strategies support effective online resource use?
  - What issues cause patients to stop using online resources?
- Recommendations for design:
  - Tools that support patient assessment of information
  - Web services that support transparency and self-advocacy in the doctor-patient relationship

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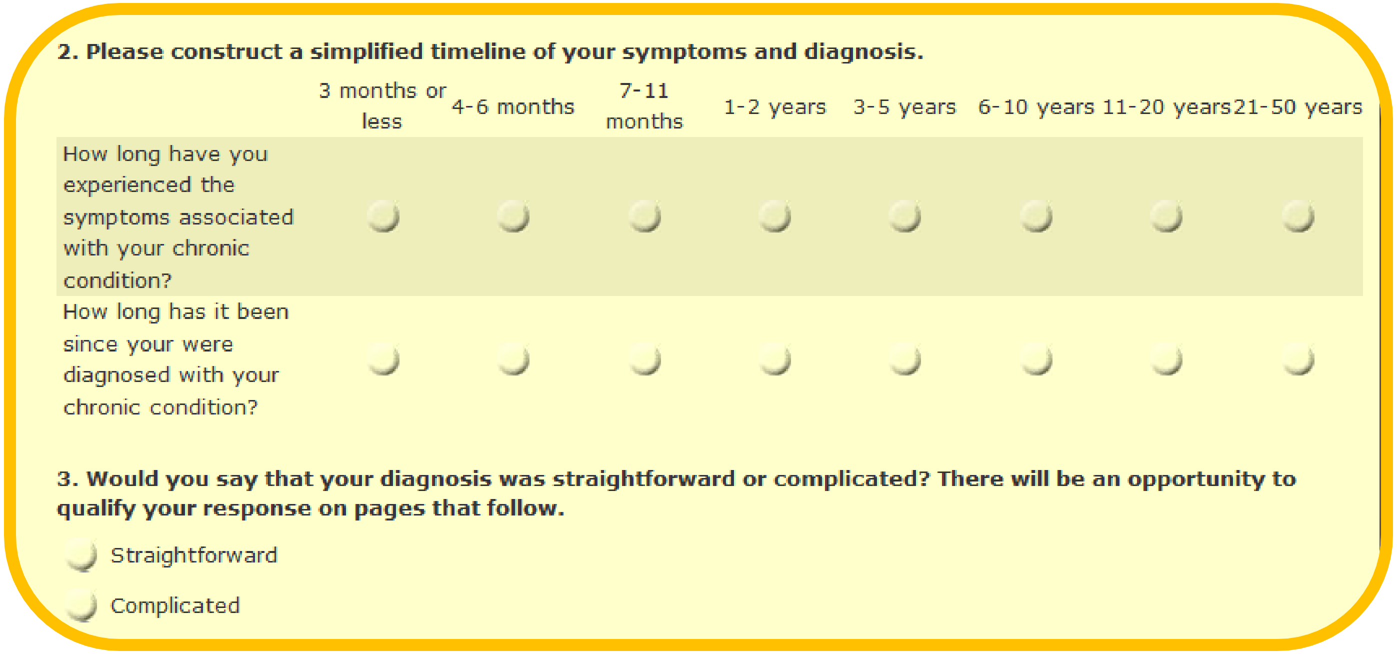
Data Collection

- Sampled online & offline
- Survey: 128 self-described Lyme disease patients
- Interviews: 21 of the survey participants



2. Please construct a simplified timeline of your symptoms and diagnosis.

	3 months or less	4-6 months	7-11 months	1-2 years	3-5 years	6-10 years	11-20 years	21-50 years
How long have you experienced the symptoms associated with your chronic condition?	○	○	○	○	○	○	○	○
How long has it been since your were diagnosed with your chronic condition?	○	○	○	○	○	○	○	○

3. Would you say that your diagnosis was straightforward or complicated? There will be an opportunity to qualify your response on pages that follow.

○ Straightforward

○ Complicated

Interview Data Analysis

Bottom-up qualitative analysis (grounded theory: *Glaser, B., & Strauss, A. The discovery of grounded theory: Strategies for qualitative research. Aldine Transaction. 1967.*)

1. Segmenting and labeling interview transcripts
2. Iterative group exercises in finding significant themes
3. Grouping annotated segments into themes
4. Contextualizing themes

- This is called “coding”
  - Entirely unrelated to programming

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Survey Results

Online Use	
Lyme specific websites used (mean)	7 [SD=3]
General health websites used	5 [SD=1]

Doctors Seen	
Number of doctors seen (mean)	11 [SD=15]
Number of doctors seen (mean) – no outliers	9 [SD 11]

Illness Timeline	
Characterized diagnosis as complicated rather than simple	82%
Median time since first becoming symptomatic	6 years
Median time for diagnosis	4 years

Survey Results

How does real-world experience with the illness relate to the use of online resources?

Predictive of increased use of online health sites:	p
Greater number of doctors consulted	= 0.02
More trust in doctor(s)	= 0.05
Having the illness for a shorter period of time	= 0.11
More overall use of the Internet	< 0.001
More overall online communication	= 0.05

Predictive of increased use of Lyme-specific sites:	p
Greater number of doctors consulted	= 0.06
Higher age (demographic variable)	= 0.05

Interview Results

Using online resources

Before diagnosis	
Unwilling to believe in an illness without reason	12
Encouraged by a friend or family member to consider Lyme disease	6
Beginning to search	9

- Some participants were reluctant to consider Lyme as a possibility
- One participant, for example, was wary of becoming an "Internet hypochondriac, so at first, I completely ignored any suggestions of things like [Lyme disease]."

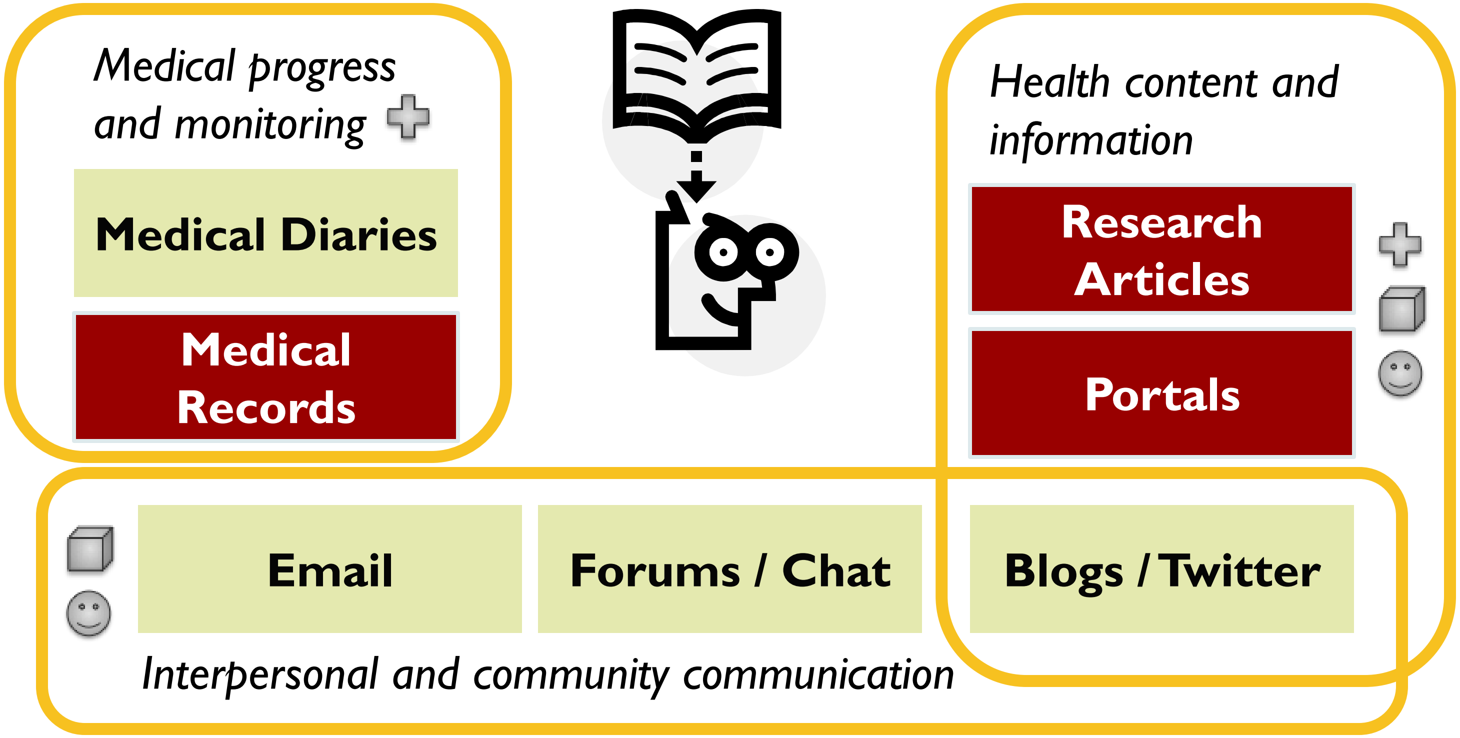
Interview Results

Using online resources

After diagnosis	
Reached a phase where they were not actively searching for resources, but stayed informed through sites that had already proven to be helpful	13
Stepped back (in some cases because volume or content of information was overwhelming)	4
Became more active in the larger Lyme disease community	12

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 (Jane)

What are these “online resources?”



Medical progress and monitoring ✚

Medical Diaries

Medical Records

Health content and information

Research Articles

Portals

✚ ◻ ☺

◻ ☺

Email

Forums / Chat

Blogs / Twitter

Interpersonal and community communication

What is the patient’s role? 🟥 content consumers 🟩 content consumers and producers

Who are the content producers?

- ◻ organizations
- ✚ doctors
- ☺ peers

Interview Results

Medical progress and monitoring (8 participants)

Activity	**n**
Tracking symptoms, sometimes daily	5
Tracking medication, other medical events, such as diagnoses, test results, and doctor's visits	3
Writing to process a difficult experience	3
Writing to help with faulty memory	1

Interview Results

Medical progress and monitoring (8 participants)

- Some participants recorded medical details for years.
- However:
  - frequency and quantity of records tended to decrease over time
  - records were not identified as useful in patient-doctor relationship
  - personal record keeping was not always helpful.
- What is the role of technology?
  - Information was occasionally stored on paper (not computers)
  - 2 participants used LymeLog

Interview Results

Interpersonal and community communication (all)

Activity	n
Introducing online resources into their immediate social networks (friends, family, and coworkers)	3
Meeting new people	11
Asking and answering questions, getting news about new treatments, to getting reviews of doctors, and/or getting support	15

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)

Interview Results

Health content and information (all)

Strategy for discerning information use	n
Researching medical information by selecting among different types of information and/or triangulating resources	15
Understanding the possibility of scams	5
Using an iterative social process to vet the trustworthiness of information	11

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. … I just don't pick any old thing to read (Jen).

Interview Results

Health content and information (all)

Strategy for discerning information use	n
Researching medical information by selecting among different types of information and/or triangulating resources	15
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… 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 is that true for you?” (Karen)

Interview Results

Health content and information (all)

Strategy for discerning information use	n
Researching medical information by selecting among different types of information and/or triangulating resources	15
Understanding the possibility of scams	5
Using an iterative social process to vet the trustworthiness of information	11

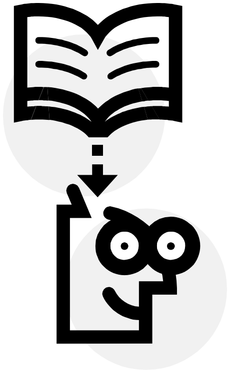
…one person will write in something or another and they will have attachments with what they're writing about, and from that attachment it takes you on into another area of Lyme, and from there you gain even more knowledge about it. So it's not just a Lyme board that has people just talking about their symptoms all the time.. (Jen)

What roles do patients play?

The manager role

Managing symptoms

Managing doctors



The warrior role

Fighting for health

Fighting for respect

Fighting for community

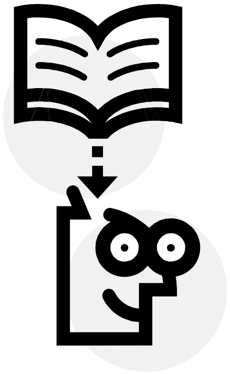
Recall: Medical progress and monitoring	**n**
Tracking symptoms, sometimes daily	5
Tracking medication, other medical events, such as diagnoses, test results, and doctor's visits	3

What roles do patients play?

The manager role

Managing symptoms

Managing doctors



The warrior role

Fighting for health

Fighting for respect

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What happened when patients brought materials to doctors?	n
Doctors responded negatively	2
Doctors explained materials, and generally encouraged this behavior	6

What roles do patients play?

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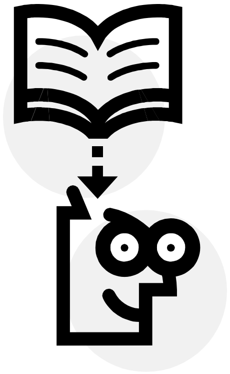
Managing symptoms

Managing doctors



The warrior role

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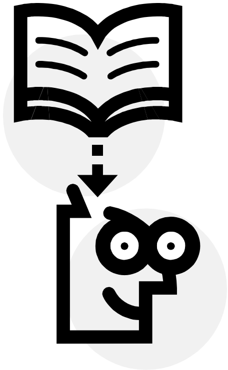
How did patients use resources available to ensure services?	n
Kept track of their symptoms to help substantiate the symptoms they were experiencing in the eyes of the doctors	3
Used HMO's online system to verify test requests and results	1

What roles do patients play?

The manager role

Managing symptoms

Managing doctors



The warrior role

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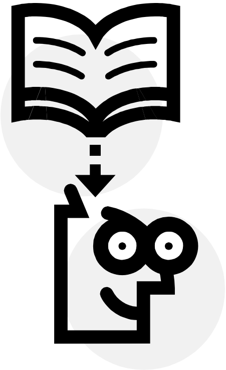
How did patients' experience with Lyme fit into their social network?	n
They were not understood, or were disbelieved	13
They were able to successfully get support after providing peers with information	4

What roles do patients play?

The manager role

Managing symptoms

Managing doctors



The warrior role

Fighting for health

Fighting for respect

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How did participants become involved?	n
Running a support group (online and offline)	4
Political activism	3
Sharing own story publicly	7

Results: Summary

- Attitudes patients expressed about online resources were largely consistent with prior work
- Unmet needs (emotional and physical) drove people online
- Trusting one's current treating physician was predictive of using online health resources – why?
  - Online resources helped almost half of the patients find a trusted doctor
  - Others said a trusted doctor encouraged online resource use
- Having taught themselves, many patients helped educate others

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Tools to Build

#1

- **Search tool** to:
  - Juxtapose information from different kinds of resources
  - Support learning sophisticated information seeking

#2

- **Tool for extraction and visualization** of viewpoints
  - Work has begun to extract information about viewpoints in other domain

#3

- **Tool for extraction and visualization** of key features associated with credibility
  - Work has been done to identify many features related to credibility

General Recommendations

- Engaging multiple aspects of the patient experience by supplementing current social resources
  - Managerial
  - Social
  - Advocacy
- Facilitating private information exchange of medical information
  - Supports patients in managing multiple doctors
  - Give patients a voice and support transparency
    - views of their own data
    - what their doctors are considering (risks and tradeoffs)

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Future Work

- Other chronic illnesses
  - This study: focus on a single, very contentious, disease.
  - Future studies: compare samples like this one to other groups
- Development of tools suggested by current data

We would like to thank…

Funders:

CRA W Committee on the Status of Women in Computing Research

NSF

Google™

And all the people who took the time to participate in this study.

Participant Population

Demographics	
Gender: Female	81%
Gender: Male	18%
Age (range)	41-50
Not married	82%
Caucasian	95%
U.S. residents	94%

Education and Employment	
Bachelors degree or above	50%
Unemployed	87%
Unable to work due to disability	62%