How Do Online Health Communities Influence Treatment Decisions? Examining Patient and Caregiver Perspectives

Presented by

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Disclosure

No relationships to disclose.
Online Health Info Seeking

- U.S. adults (60%) and Internet users (80%) regularly seek health information online

What are they seeking?  
- Symptoms
- Peers and social support
- Treatment and drug info
- Health insurance info

Where do they go?  
- Search engines (Google)
- Health sites (WebMD, ACS)
- Online health communities
What Are Online Health Communities?

Internet-based forums focused on specific health and wellness topics where individuals dialogue with one another.\textsuperscript{6-8}
What Do We Know about OHCs?

Discussion Topics
- Treatment options and medications are common topics
- Social support
- Intervention adherence
- Patient-provider discussions
- Emotional well-being
- Medical knowledge
- Informed treatment decisions

Participation
- Internet Users: 20%
- Internet Users with Chronic Illnesses: 25%
Study Purpose

- **Membership.** Where, when, and why do people join?
- **Reputation / Credibility.** How do people assess reputation of community and credibility of health information?
- **Privacy.** How important is privacy? How do people protect it within communities?
- **Treatment Discussions.** What types of treatment are discussed? How balanced are discussions? Sources of info?
- **Influence on Health Decisions.** What role do OHCs play in health and treatment decisions?
Study Design

General Online Community Members

<table>
<thead>
<tr>
<th>Group</th>
<th>n</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group 1</td>
<td>10</td>
<td>Bethesda, MD</td>
</tr>
<tr>
<td>Group 2</td>
<td>9</td>
<td>Bethesda, MD</td>
</tr>
<tr>
<td>Group 3</td>
<td>8</td>
<td>Bethesda, MD</td>
</tr>
</tbody>
</table>

Active / Heavy Users

<table>
<thead>
<tr>
<th>Group</th>
<th>n</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group 4</td>
<td>10</td>
<td>Raleigh, NC</td>
</tr>
<tr>
<td>Group 5</td>
<td>9</td>
<td>Chicago, IL</td>
</tr>
</tbody>
</table>

Passive / Light Users

<table>
<thead>
<tr>
<th>Group</th>
<th>n</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group 6</td>
<td>10</td>
<td>Raleigh, NC</td>
</tr>
<tr>
<td>Group 7</td>
<td>9</td>
<td>Chicago, IL</td>
</tr>
</tbody>
</table>

Recent Diagnosis

<table>
<thead>
<tr>
<th>Group</th>
<th>n</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group 8</td>
<td>8</td>
<td>Virtual</td>
</tr>
</tbody>
</table>

Treatment Decision

<table>
<thead>
<tr>
<th>Group</th>
<th>n</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group 9</td>
<td>8</td>
<td>Virtual</td>
</tr>
</tbody>
</table>

Core Community

<table>
<thead>
<tr>
<th>Group</th>
<th>n</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group 10</td>
<td>8</td>
<td>Virtual</td>
</tr>
</tbody>
</table>
Participants / Eligibility

Timeframe
- September – December 2011

Study Participants
- 89 members of active, verified OHCs
- OHCs focused on illness (not wellness)

Core Eligibility Criteria
- Age 18 or older
- Not a healthcare provider / pharmaceutical employee
- English speaking
- Community participation not part of job
## Participants / Eligibility

### Group Eligibility Criteria

<table>
<thead>
<tr>
<th>Group</th>
<th>Population</th>
<th>Illness</th>
<th>Visit Frequency</th>
<th>Other Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-3</td>
<td>General Members</td>
<td>--</td>
<td>Once / month</td>
<td>--</td>
</tr>
<tr>
<td>4-5</td>
<td>Active Users</td>
<td>--</td>
<td>Once / week</td>
<td>More likely to post</td>
</tr>
<tr>
<td>6-7</td>
<td>Passive Users</td>
<td>--</td>
<td>Less than once / week</td>
<td>More likely to read</td>
</tr>
<tr>
<td>8</td>
<td>Recent Diagnosis</td>
<td>Fibromyalgia</td>
<td>Once / month</td>
<td>Diagnosed &lt; 1 year</td>
</tr>
<tr>
<td>9</td>
<td>Treatment Decision</td>
<td>Depression</td>
<td>Once / month</td>
<td>Major treatment decision &lt; 1 year</td>
</tr>
<tr>
<td>10</td>
<td>Core Community</td>
<td>Multiple Sclerosis</td>
<td>Once / week</td>
<td>Member of PatientsLikeMe MS group</td>
</tr>
</tbody>
</table>
Data Collection and Analysis

In-Person Groups
- Structured, moderated discussion
- Two-hour sessions

Virtual Groups
- Structured, live-chat forums
- One-hour sessions

Analysis\textsuperscript{17-19}
- Independent coding of verbatim transcripts in NVivo 9.2
- Thematic analysis
Community Membership

- Membership in four types of OHCs

**Mega Sites**
- WebMD
- Yahoo Health Groups

**Health Boards**

**Non-Profit / Medical**
- CCFA
- ADA

**Single Illness**
- RA Warrior
- Obesity Help

**Insurer**
- BCBS
Community Membership

Finding Communities
- Majority stumble across OHCs during Web search (e.g., Google)
- Referrals from family, friends, and healthcare providers

Membership Timing
- Most join post-diagnosis
- Some join pre-diagnosis (exploring symptoms, seeking answers)

“The frustration of not knowing what this is drove me to find the community.”

“I usually start with Google, and I’ll do a search on something and then it’ll bring me to a community—like a new community—and then I’ll learn about it.”
Community Membership

Reasons for Membership

- Learn about illness and treatment options
- Learn about family/friend’s illness
- Seek support
- Geographic limitations

“I wanted to learn about my condition.”

“I didn’t know much about MS and wanted to find out more details. I also live in a rural area, and we have no support groups.”

“[I wanted] to know that there were other people out there with the same issue.”
Community Reputation

Importance of Reputation

High Importance
- Goal: Learn about illness
- Concerned about accuracy

Limited Importance
- Goal: Seek support
- Hear different perspectives

Signs of Reputable Community
- Credible sources/citations
- Relevant, current postings
- High level of activity
- Sponsorships / endorsements
- Established community
- Mission, founders, background
Member and Information Credibility

- Healthy skepticism of member identities and site information
- Distrust of self-identified healthcare professionals

**Credible Members**
- Scan profiles
- Examine provider credentials, education

**Credible Information**
- Detailed and in-depth
- Mirrors own experience
- Community consensus
- Cross-check against other resources
Privacy Concerns

Concerned
- Keep diagnosis private
- Desire anonymity
- Combat spam

Not Concerned
- I Have Control
- Privacy important
- Control info shared

No Privacy
- No privacy in digital age

Protective Behaviors
- Dummy e-mail accounts
- Anonymous usernames
- Fake profiles
- Limit personal sharing
Treatment Discussions

Types of Treatment
- Prescription / OTC drugs
- Behavioral therapy (diet, exercise, meditation)
- Alternative therapies (herbs, acupuncture)
- Clinic-based therapy (chemo, surgery)

Treatment Topics
- Effectiveness
- Side effects
- Recovery period
- Cost / insurance
- Current events (drug approvals)
Treatment Discussions

Sources of Information
- Personal experiences most common
- Factual references cited occasionally

Balance of Pros vs. Cons
- Advantages and disadvantages tend to balance out across message threads
- Emphasis on multiple sources

“You still have to take everything with a grain of salt.”

“I mean, you have to use multiple sources to really find out what’s going on. You can’t go to one Web site and read it and say ‘Okay, this is how it’s going to be.’”
Role in Health Decisions

- **Research**
  - Search engines
  - Medical sites

- **Existing Knowledge**

- **Provider Discussion**
  - Inform questions
  - Verify OHC info

- **Self-Care Activity**

- **Treatment Decision**
Conclusions

- **Need for Answers.** OHC membership motivated by desire to learn more about own (or loved one’s) health condition.

- **Stumble Across OHCs.** Membership idea often planted by Web search results or self-directed research.

- **Cautious.** Healthy skepticism of members, information.

- **Verify Information.** Cross-check OHC info with online resources and healthcare providers.

- **Personal Experiences.** Discussions revolve around personal experiences with medications, self-care.

- **Starting Point.** OHC info used as starting point for health decisions. Supplements provider advice, other research.
Study Team & Authors

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- Jacqueline Amoozegar
- Rebecca Moultrie
- Olivia Taylor

U.S. Food and Drug Administration
- Helen Sullivan
- Amie O’Donoghue
- Kathryn Aikin
References


References


14 Frost, J.H., & Massagli, M.P. (2008). Social uses of personal health information within PatientsLikeMe, an online patient community: What can happen when patients have access to one another’s data. *Journal of Medical Internet Research*; 10(3): e15.


