Online Activism: Advocacy in Internet Cancer Communities

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The 135th Annual Meeting of APHA, 2007

3060.0: Monday, November 05, 2007 - 8:30 AM

Goal:

To learn about advocacy processes in Lung and Chronic Lymphocytic Leukemia (CLL) Internet Cancer Communities (ICCs).

Rise in Internet Cancer Communities (ICCs) on the Examined Server

- 1994   4
- 1998   70+
- 2001   99
- 2004   123
- 2005 Nov.   163

- 80% of Internet users sought health information online
- 56 million people in the United States actively sought information about chronic diseases

Prior Research of ICCs

Focused on social support provision.
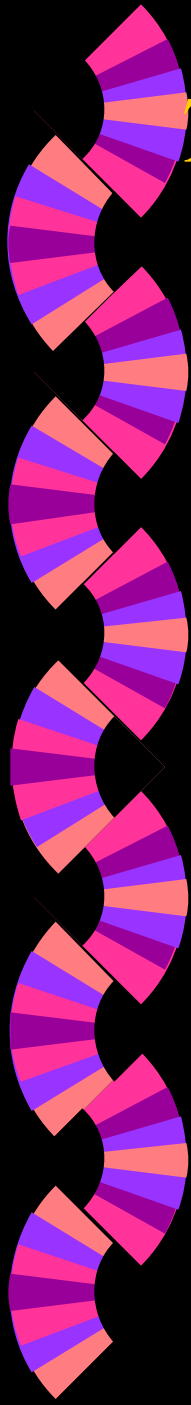
Uses identified:

- Exchange of informational support
- Exchange of emotional support
- Concerns regarding conflicts and offensive communication
- Advocacy-related purposes (Ginossar, 2007)

Previous Study[1]: Content of Email Messages of CLL and Lung ICCs by

(1) Information reply (30%)

(2) Information seeking (17%)

(3) Provision of unsolicited information (13%)

(4) Other (13%)

(5) Emotional support only (12%)

(6) Conflicts between ICCs members (9%)

(7) <u>Political and advocacy (6%)</u>

1. Ginossar, T. Online Participation: A Content Analysis of Differences in Utilization of Two Online Cancer Communities by Men and Women, Patients and Family Members (in press, *Health Communication*).

Theoretical Framework: Empowerment Theory

<u>Empowerment</u>

A social action process that promotes participation of people, organizations, and communities in gaining control over their lives in their communities and larger society.

<u>Empowerment Processes</u>

Actions, activities, or structures may be empowering.

Outcome of such processes result in a level of being empowered

Theoretical Framework (cont.)

- FTF Activist organizations provide collective setting
- social or political activism and personal self-advocacy are related

(Brashers et al., 2000; 2002).

It is unknown whether online communities might provide similar processes.

Methods

- Participation/observation of lung and CLL ICCs.

- Qualitative thematic analysis of email messages that related to advocacy.

Findings

1. Self-advocacy in communicating with physicians

Potential influence was direct and indirect

- The groups facilitated information seeking
- Provided information needed for successful communication with physicians
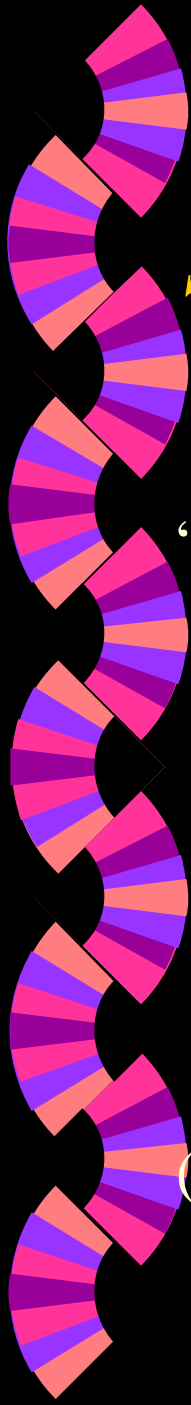- Members encouraged each other to advocate for themselves

Findings (Cont.):
Self-advocacy in communication with physicians

...One of the first valuable bits of advice I took to heart (from the list moderator) was to get copies of all my test results. As a result of reading my own CT report I discovered that my onc had greatly exaggerated the findings when he told me the results. I avoided being pushed into treatment last Jan. and am still doing fine in W&W with no symptoms. I changed oncs; he agreed with my decision to wait and I'm much happier with this Dr.
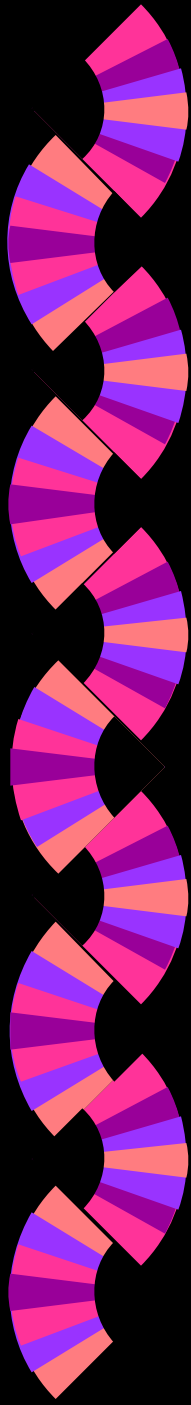
(an email posted to the CLL ICC)

Findings (Cont.):
Self-advocacy in communication with physicians

"I agree with you completely that we must be our own advocates and take responsibility for educating ourselves in order to receive the best care. When I was first diagnosed, I knew nothing about lung cancer except it kills people. I was certain that I had no choice but to prepare for my death. The people on this list have taught me to ask questions, to read and learn and to decide what I want to happen in my treatment".

(an email posted to the Lung ICC)

Findings (Cont.):
Self-advocacy in communication with physicians

"..... my point is that no matter which treatment he is on, find out how they are measuring the results and as soon as it's not working, be ready with a second line of treatment."

(A sister of a lung patient)

Findings (Cont.):
Social advocacy in ICCs

2. The ICCs emerged as sites for social advocacy processes

(a) Raising awareness to cancer related-issues:

The examined ICCs were sites for proceeses of raising awareness of members, and of attempting to "spread the word" to the general public about policy-related issues.

Findings (Cont.):
Social advocacy in ICCs

2.a. Processes of raising awareness

Is it possible that we do ourselves a disservice by not talking about CLL? [in] many other serious illnesses[…] The patients are not shunned by others as some diagnosed with cancer are. I believe that education of the public is the key to changing attitudes about cancer, and especially in our form of this disease. Knowledge is power and in many cases equals $$$ for research.

Findings (Cont.):
Social advocacy in ICCs

"With 170,000 deaths from lung cancer expected this year …Why can't the State fund a web site with all major cancers posted. Where we can get info to trials, treatments, etc., using the 'tobacco settlement moneys'. The Federal Government should also be more involve in finding and funding for Cancer. What happened to Richard Nixon's war on cancer?"

A letter to Political Representatives, posted by a patient to the Lung ICC.

Findings (Cont.):
Social advocacy in ICCs

(b) Organizing rallies and fund raising

- The examined ICCs provided opportunities for existing FTF organizations to advocate to their constituents and request support.

- The examined ICCs allowed for emergance of new organizations

Findings (Cont.):
Social advocacy in ICCs

2.b. Rallies and fundraisers

I have not responded to the list before, but I thought you might find this interesting. I in combination with other lung cancer survivors along with healthly supporters have formed an organization[…] Our total focus is dedicated to funding lung cancer research. It just so happens that two of us our very young and never smoked so we are even more adamant about finding a cure through raising money for research. We are currently working on our first fund raising project

- Stigma associated with having lung cancer.

Findings (Cont.):

3. Exchange of information and opinions about larger policy-related issues.

Instead of pumping millions of dollars into "just saying no" to smoking, they need to fund lung cancer research or else there will be no cure. The government has made it clear that "not smoking" is the cure and are telling us "tough luck".

Conclusions and Implications

- ICCs are used for online advocacy.

- The groups promote collective action.

- Participation in ICCs might be similar to FTF participation in advocacy organizations.

- Digital divide may lead to greater disadvantage of patients and social groups who do not have equal access to the Internet.

Future Research

- Increase the scope of ICCs examined.

- Differences between FTF and online activists.

- Differences between ICCs members who participate in advocacy and those who do not.

- Effects of online advocacy on health outcomes.

- Effects of participation on advocacy efforts and actual outcomes in the community.

- Barriers to participation & effects of digital divide.

- Usage of multiple data collection methods.