



Supporting cancer patients through the continuum of care: a view from the age of social networks and computer-mediated communication

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ABSTRACT

Almost since its inception, the Internet has been used by ordinary people to connect with peers and to exchange health-related information and support. With the rapid development of software applications deliberately designed to facilitate social interaction, a new era is dawning in which patients and their loved ones can collaboratively build knowledge related to coping with illness, while meeting their mutual supportive care needs in a timely way, regardless of location. In this article, we provide background information on the use of “one-to-one” (for example, e-mail), “one-to-many” (for example, e-mail lists), and “many-to-many” (for example, message boards and chat rooms, and more recently, applications associated with Web 2.0) computer-mediated communication to nurture health-related social networks and online supportive care. We also discuss research that has investigated the use of social networks by patients, highlight opportunities for health professionals in this area, and describe new advances that are fuelling this new era of collaboration in the management of cancer.

KEY WORDS

Social support, supportive care, computer-mediated communication, social networks, Internet

1. INTRODUCTION

Illness support communities on the Internet ... invaluable resources for clinicians; ... smarter, or at least more comprehensive, than many physicians—even medical specialists.
— Hoch & Ferguson, 2005¹

Selma, a 45-year-old journalist and single parent with two teenage children, is a breast cancer survivor. One year ago, she underwent a partial mastectomy to remove a malignant mass in her left breast, followed by a course of radiation therapy. Before her treatment, Selma joined a breast cancer e-mail list to learn about various cancer treatments and their side effects from others who had already experienced them. At the same

time, her two teenage daughters created a group on Facebook for teens whose parents have cancer. These social networking activities helped Selma and her girls to address some of their fears and concerns, enabling them to be more knowledgeable and prepared for interactions with health professionals and upcoming cancer treatments. While undergoing treatment, Selma developed, with help from her daughters, a personal care journey profile on the CarePages social network Web site to keep her extended family and friends informed about her treatment journey and to gain timely support from them in the process.

Selma is now in remission. However, she struggles with consistent upper arm and chest pain. She continues to participate on the breast cancer e-mail list as self-appointed support provider, and she has recently rejoined the cancer pain e-mail list to learn about alternative methods to achieve relief.

In this article, we provide information on the types of computer-mediated communication technologies traditionally used by cancer patients, we present current evidence on the use and effects of those technologies, and we explore the role of emerging social networking technologies, which are now considerably more collaborative, adaptive, and interactive than their predecessors were.

2. DISCUSSION

Only a few years ago, Selma and her children may not have been able to access health-related information and support from their social networks to the extent that technology now makes possible. In the short time that the Internet has been available to the general public, its use for the finding and sharing of information about health has increased exponentially². Almost two thirds of cancer patients from high-income countries use the Internet either directly or indirectly (through friends and family) as a supportive care resource³, and research suggests that it continues to play an important role after medical treatment has ended⁴.

Cancer patients value practical and experiential information from other patients⁵, which has been reported to be an important component of symptom management among breast cancer patients⁶. They also

report being dissatisfied with the quality and amount of information that they receive from health professionals^{7,8}, and they often seek online support from other cancer patients to validate unanswered questions and concerns⁹. In addition, many cancer patients participate in online support groups simply to help others¹⁰.

The exact mechanisms by which social relationships affect health remains unclear, but nearly 30 years of research has demonstrated that such relationships have a powerful effect on physical and mental health and that they may extend survival¹¹. The Internet represents a convenient means for cancer patients and their loved ones to support each other through the disease experience. Moreover, there is little evidence to support the claim of harm resulting from the use of poor-quality information obtained from the Internet¹². Researchers have demonstrated that users of online communities are competent at deciphering “good” from “bad” information, put considerable effort into ensuring that the information shared is accurate, and correct questionable or misleading statements as they occur^{1,13,14}.

2.1 Computer-Mediated Communication

Initially there were three basic ways in which technology was used to support communication:

- e-mail, including e-mail lists or mailing lists, also commonly called “listservs” from the name of a popular software package for managing such lists (Listserv: L-Soft International, Landover, MD, U.S.A.);
- asynchronous discussion forums, also known as message or bulletin boards; and
- synchronous (real-time) discussion forums, also known as chat rooms¹⁵.

Collectively (see Table 1), these technologies are known as tools for computer-mediated communication (CMC).

Electronic mail was originally designed as way for one person to communicate with another (“one-to-one”). Software applications were then developed to provide a means for “one-to-many” exchanges, commonly known as e-mail lists. Other technologies such as newsgroups and message boards were also developed that supported a “many-to-many” model of communication¹⁶.

Using these various CMC technologies, online support groups or communities formed. These applications have since been successfully used for many years to facilitate the exchange of health information before, during, and after cancer treatment¹⁷. To date, most researchers have examined the use of e-mail lists and message boards; fewer have investigated synchronous technologies such as chat rooms. The next subsection reviews the current understanding of the use of e-mail lists, message boards, and chat rooms in relation to support among cancer patients.

2.1.1 Online Support Groups

Surveys of new subscribers to cancer e-mail lists suggest that most patients join to find out about “the latest cancer treatments” and methods to “deal with cancer” and “manage side effects”¹⁰. In addition, almost half of new subscribers report joining specifically to “get support from people with the same type of cancer.” A similar percentage report joining simply to “help others”¹⁰.

Online support groups can provide group members with a safe, relatively anonymous space in which to communicate about sensitive and potentially stigmatizing topics^{9,13}. Sharing experiences with similar others has been reported to reduce feelings of isolation and uncertainty regarding prognosis and ambiguous painful symptoms¹⁸, to validate concerns ignored by health professionals⁹, and to enable cancer patients to become better informed about their condition and to formulate questions for their health professionals¹⁹. In addition, numerous psychosocial benefits are gained from helping others^{9,18,19}.

Results of randomized controlled studies of online support groups for breast cancer patients have shown that such groups can reduce depression, stress, and reactions to pain, and can contribute to greater emotional well-being, social support, and post-traumatic growth^{20–22}. Much less research is available on the use and effect of unmoderated, consumer-led communities that attract the bulk of online traffic¹⁵.

2.1.2 Web 2.0 and Beyond

Recently a shift in focus and philosophy has occurred related to the technology used on the Internet. Called “Web 2.0,” this change has been defined as “a set of economic, social, and technological trends that collectively form the basis for the next generation of the Internet—a more mature, effective medium characterized by participation, openness, and network effects”²³.

Web 2.0 is intended to encapsulate efforts to promote collective participation among Internet users. Various principles are associated with Web 2.0 (see Table 1), some of which include social collaboration as an element. These efforts are supported by various software applications—developed independently, but similarly themed—with the underlying principle of supporting collaboration. These applications have been collectively called “social software”²⁴.

“Web 2.0” may simply represent new jargon for what the Web was meant to achieve from the outset²⁵, but the applications it has become known to represent are markedly different than those of earlier Web sites, whose static content was governed by webmasters and broadcast mainly through hypertext links²⁶. Unlike those Web sites, in which content was generated by one person for many, sites using Web 2.0 technologies are designed to support the addition and editing of content by anyone (sometimes restricted to an “anyone” who is a member of a specific

TABLE 1 Computer-mediated communication (CMC) formats

<i>Format</i>	<i>Description</i>	<i>Example</i>
E-mail	A software application that allows one or more people to exchange information by sending a private or individual message.	A patient could send a friend a message by e-mail updating her on her medical condition.
E-mail list	A software application that manages the exchange of multiple messages by e-mail. A message sent to the list by an individual member is distributed to all subscribed members.	The Association of Cancer Online Resources (www.acor.org) offers more than 150 e-mail lists for people affected by cancer and related disorders.
Message or bulletin boards or discussion forums (asynchronous)	A Web-based application that “threads” messages and related replies, providing a forum for discussing various topics. The messages are not sent to individual addresses, but can be read by anyone with Internet access.	Yahoo!Groups (ca.groups.yahoo.com) is a prominent discussion forum provider, which, as of March 2008, listed more than 6000 groups dedicated to cancer.
Chat rooms (synchronous)	A Web-based application that provides a discussion “area” that accommodates synchronous (real-time) exchange of information. Multiple discussions can occur simultaneously, as result chats are often moderated.	OncoChat (www.oncochat.org) is an online support network that provides opportunities for people affected by cancer to communicate with each other in real-time.
Blogs (web logs)	A Web-based journal or diary in which entries are added by one or more authors usually in chronologic order. Readers can add comments to each blog entry, further contributing to the content.	The Migraineur (migraineur.wordpress.com) is a blog created by a migraine sufferer. The author shares her daily struggles with migraines, prompting other migraine sufferers to provide comments about their own experiences.
Wikis	A Web-based application that allows users to freely write and edit online material without using other software applications or uploading files to a server. The term wiki originated from the Hawaiian phrase “wiki wiki,” meaning quick.	Popular examples of health wikis include www.wikihealth.com and www.wikicancer.org . Users of these sites can contribute content directly to the site, providing a collaborative or social element to knowledge-building.
Social bookmarking	A Web-based application that an individual can use to save and share favourite Web sites with others online. The individual submitting the saved Web page labels or tags it with various key words, so that readers can search for relevant information by using the key word tags.	del.i.cious and www.digg.com are examples of sites that offer centralized bookmarking of a third-party site’s content; other sites permit tagging of local-site content.
Social network sites	A Web-based service that allows individuals to construct a profile, articulate a set of other people on the service with whom they share a connection, and view their list of connections and the lists made by others. Social network sites usually contain many Web-based applications that allow users to interact and share resources in different ways.	PatientsLikeMe (www.patientslikem.com) is social network site for people with life-changing diseases. Users construct personal profiles that provide information about their disease experiences, establish connections with other users of the site, and share supportive information and resources.

community). For patients participating in health communities, the most important aspect is the deliberate effort to acknowledge, accommodate, and capture the power of the social aspects of Web 2.0 technology. The encouragement of shared activity shows an inherent understanding of the importance of collaboratively generated knowledge. It is by mutual engagement that this shared repertoire of knowledge will be developed.

2.1.3 Online Social Network Sites

Since the last decade of the 20th century, social networking technologies and social network sites have been proliferating and growing in popularity. The recent focus on Web 2.0 is likely to further increase the

rate of this proliferation. Previous CMC technologies facilitated interaction, exchange, and community building, but they did not enable their users to make visible their social networks—a key feature of the sites commonly known for social networking.

Boyd and Ellison²⁷ define social network sites as Web-based services that individuals can use

- to construct a public or semipublic profile within a bounded system;
- articulate a list of other users with whom they share a connection; and
- view and browse their list of connections and those made by others within the system.

TABLE II Web 2.0 principles and health applications

<i>Web 2.0 principle</i>	<i>Description</i>	<i>Health application</i>
Harnessing collective intelligence	As more people contribute to a service, it improves (for example, Wikipedia).	Participants can develop content both by sharing anecdotal or experiential information and by interpreting journal articles or other medical documents.
Data prominence	Information (data) at a Web site is as important as how the site functions—content created collaboratively, even more so.	OPIMEC (www.opimec.com) is a site that promotes the identification and adoption of innovative practices for chronic disease management. It includes an evolving taxonomy of chronic disease terms and practices, collaboratively developed by the users of the site, in an effort to establish a common language to support chronic disease management globally.
Innovative content assembly	A remix or mash-up of data and services such that one program can use features found in another.	HeathMap (healthmap.org) is a global disease alert mapping system that integrates news reports on disease outbreaks with a real-time mapping system. It provides a graphical display of the location of the disease outbreak and access to the original news report.
Co-creation by users	The mixing of the desktop and online experiences—for example, collaborative editing software that allows for multiple users to contribute.	Software applications under the Web 2.0 umbrella such as wikis (www.wikihealth.com) and blogs (www.chronicfatigue.com/wordpress/) demonstrate the ease with which content can be created collaboratively.
Software above the level of a single device	Handheld devices such as personal digital assistants and cell phones are now used to connect to the Internet, changing how and where content is viewed.	A mobile phone–based remote patient monitoring system for chronic disease management (www.ehealthinnovation.org/?q=dh) utilizes mobile phones and newly introduced Bluetooth-enabled medical devices to transmit patient physiologic information from the home to a central repository, where alerts and reports can be generated and delivered to both patient and provider.
Perpetual beta	Versioned software is obsolete—for example, Google does not require downloads and installations when it is updated.	Seamless changes to the interface mean less involvement in the technology for the site user. An example in a health care context would be a site that offers information in a wiki or blog that updates the software application without an individual being required to install or update their computer.
Leveraging the long tail	The “long tail” is the area at the extremes of a distribution curve, usually representing the smallest percentages. In relation to the Web, this term refers to the vast number of smaller sites devoted to more esoteric content.	Rare illnesses could be considered a long tail in online health. Many Web sites and other online information sources serve people with more obscure illnesses. Anecdotal information shared by patients with these illnesses is an example of how individuals leverage their power by participating with others in the same circumstances.

Most social network sites help to maintain pre-existing social networks; others enable strangers to connect based on shared interests²⁷. They vary in the extent to which they incorporate information and communication technologies that facilitate the sharing of content and collaboration in the form of applications such as blogs, wikis, and social bookmarking²⁷ (see Table 1).

Social network sites could provide access to a more extensive and socially diverse network of peers than online support groups do, thus facilitating access to a wider array of supportive information and services. Social network sites thus provide further evidence of the strength of “weak ties” (relationships that lack the intimacy and frequency of interaction characteristic of “strong ties” to family and close friends)²⁸. In general, strong ties provide more social support than weak

ties do²⁹. However, weak ties can assist people in times of stress and uncertainty in ways that their stronger ties cannot³⁰.

Some understanding has been reached regarding the use and effects of online support groups in cancer, but no studies of social network sites as supportive care resources for patients and their loved ones appear to have been published. As suggested by Boyd and Ellison²⁷, given that social network sites are primarily structured around people rather than interests, these sites provide excellent scholarship opportunities into the use and effects of collaborative social software.

2.1.4 “Invaluable Resources for Clinicians”

Most health systems throughout the world do not yet adequately deal with the confluence of complex, time-intensive supportive care issues that people living with

cancer and their loved ones have to face daily. Many of these issues are neglected because of the fractured nature of care delivery and the lack of mechanisms and incentives to permit their timely management. As a result, caregiving conducted by family members increases³¹. Psychosocial distress has been reported to be prevalent in up to one third of cancer patients undergoing treatment³² and in more than half of family caregivers³³. Moreover, advances in early detection and treatment modalities have resulted in a growing population of cancer survivors³⁴, many of whom are struggling with the physical and psychosocial effects of the disease well beyond treatment³⁵, with little support from the system.

It is now recognized that meeting the psychosocial needs of patients living with cancer helps them to better cope with the disease, to have a better quality of life, and to rely less on medical services¹⁷. Patients may be able to overcome many of these challenges with support from peers. Online social networking tools could provide a viable and effective way for patients and loved ones to collaboratively meet their supportive care needs in a timely way.

By participating in online social networks, health professionals can also gain insight into aspects of the patient experience. These insights may help them when they provide care and treatments. Trends in disease progression that are not readily reported to physicians because of time limitations may be shared in this context. Physicians Hoch and Ferguson¹ reported “learning a great deal” from BrainTalk Communities, an online community for people affected by neurologic conditions. The extent of sympathy and support and of practical and medical information exchanged within this online community far surpassed “anything a patient might conceivably expect to receive at a doctor’s office”¹.

3. CONCLUSIONS

It has been well documented that people want health information and have been using the Internet to obtain the information they seek. An understanding is now beginning to emerge concerning the importance of supportive care and patient–patient collaboration in this context. Emerging social networking approaches are heralding a new era in which patients and their loved ones can increase their capacity to build knowledge related to their illness. These approaches are also providing a means for mutual support and information trading about treatment decisions and care strategies so as to engage in self-management and to address psychosocial concerns.

Online social networks have the potential to transform the relationships between health professionals and cancer survivors and their loved ones. Beyond the immediate potential to improve cancer care, these networking tools could have a powerful levelling effect on the playing field between the public and health

professionals through the entire health care system and across the whole spectrum of care. However, the perceived threat posed to the health establishment by the use of CMC is of concern among health professionals and patients and must be addressed¹³. It has been suggested that “It is not Internet information *per se*, but how a physician reacts in response, which determines Internet health information’s effect on the physician–patient relationship”³⁶. We believe that if health professionals had a better appreciation of the importance of these environments to their patients and the right incentives to participate, some of the concerns could be alleviated.

It took more than 100 years for the telephone to begin playing a key role as a tool to improve communication between health professionals and patients and their loved ones. We cannot afford to wait much longer to harness the power of online social networking to address the growing unmet supportive care needs of people living with cancer. The opportunity to avoid a great deal of unnecessary suffering openly and efficiently is unprecedented. Let’s seize it ... together.

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