

Web 2.0 and Chronic Illness: New Horizons, New Opportunities

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Judging by the early evidence, Web 2.0 heralds a breakthrough opportunity to empower healthcare consumers of all types, especially those suffering from different forms of chronic illnesses. In this article, I use data gathered from a popular social networking website – MySpace.com – to show that this opportunity may be greatest for heavily stigmatized chronic health issues, such as obesity and mental illness. I also discuss how hospitals and health regions can benefit from and contribute to this fast-growing phenomenon.

Blogs (i.e., journal entries) and wikis (collaborative editing websites), early tools of the Web 2.0 era, facilitate participation, conversation and community. New gaming technology that imitates real life – including the popular three-dimensional Second Life (<http://secondlife.com>), with 8.9 million residents, or “avatars” – is revolutionizing how clinicians are trained in cyberspace and how patients interact with one another. (On Second Life, Good Will Stacey is a medical librarian who answers members’ questions. Members can visit Health Info Island and the Consumer Health Library, which educates visitors on how to evaluate the credibility of health information sources.) Most important, Web 2.0 offers solace and commu-

nity to many people with chronic illness; often isolated and not knowing where to turn for help, patients with chronic disease are increasingly communicating in cyberspace and are leading the Web 2.0 revolution.

Terminology

Social networks are online social structures consisting of “nodes,” or individuals linked together through a common interest or theme. Individuals belonging to a social network usually post an online profile detailing their interests, origin and background (albeit one’s real identity can be masked). Using these profiles, the social network can then facilitate connections among like-minded people and support their online meetings, conversations and collaborations (Figure 1).

As a technology application, *Web 2.0* refers to open sharing and collaboration on the World Wide Web and is based on the principle that the more information is exchanged, the more open, creative and meaningful that information becomes to the participants (Cross and Parker 2004). Web 2.0 has been referred to as “social software” because it brings people from around the globe together in an interactive virtual space where information

can be continually requested, exchanged, refined and reinterpreted. Table 1 presents Web 2.0 applications and meanings.

Not too long ago, a person's experience with his or her computer was a solitary one. Just in the past three years, Web 2.0 has spawned a new era of collaboration, where people learn through conversation rather than by reading static information posted on a website. The new global enthusiasm for Web 2.0 – and, in particular, the emerging application of Web 2.0 to chronic illness – may be considered a proof of political scientist Robert Putnam's hypothesis that improved physical and mental health can result from generating social capital through increased networks of trust (Putnam 2000).

Consider MySpace (www.myspace.com), an early pioneer in Web 2.0 and the sixth most popular website on the planet (ranked ninth in Canada [Alexa Internet 2007]), reaching on average over 5.3% of global Internet users every day, including roughly 900,000 Canadians (Internet World Stats 2007) – more than the daily circulation of any Canadian newspaper. Unlike, say, a newspaper, which readers might scan and then throw away, visitors to sites like MySpace engage actively in communities, posting their own videos, creating or editing blogs and collaborating on ideas that remain on the site in perpetuity. In this context, it is illuminating that the largest proportion of the most popular communities on MySpace does not relate to entertainment, sports or politics – but to chronic illness. Table

2 describes the most popular health-related MySpace communities and their relative popularity ranking on the site.

An estimated three million Canadians (Internet World Stats 2007) visit another hugely popular social networking site, Facebook (www.facebook.com), on any given day. This Web 2.0 universe was created just three years ago and is today the most popular website among Canadians. While there, users connect with people as friends or confidantes; they participate in communities where members share similar concerns and ambitions relating to politics, culture, art – and chronic illness. As of August 2007, there were roughly 1,200 Facebook communities advocating for cures for different chronic illnesses. The Canadian Cancer Society's Facebook community included, as of the time of this writing, 14,730 members from around the world; 3,732 Facebook users had registered as members for the cause to find a cure for Crohn's disease and ulcerative colitis. Just one of the many suicide awareness and prevention communities on Facebook boasts over 21,000 members.

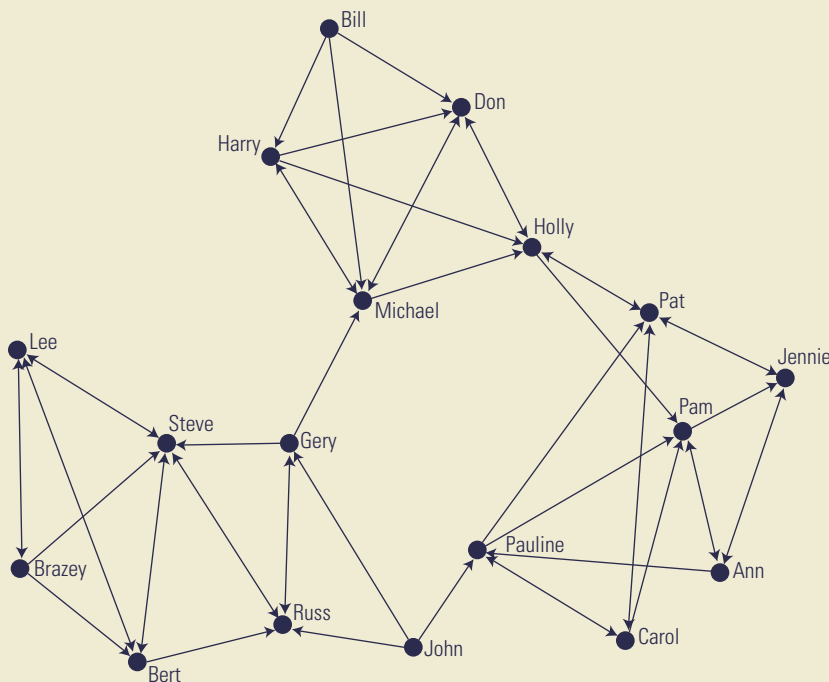
How Significant Is the Web 2.0 Phenomenon for Healthcare?

Web 2.0 is not a fad. Six of the top 20 websites in Canada have as their focus social networking features such as blogging. It is probably not a coincidence that 2003, the year that saw Web 2.0 begin its ascent in popularity, was the same year that

the Internet surpassed the physician as Canadians' primary source for health information (IBM Business Consulting Services 2006, March 8). Many of the world's most trusted and most-visited health information websites, such as WebMD (www.webmd.com), now invite participant interaction through blogging tools.

Whether via blogs or RSS feeds (*really simple syndication*, or aggregated information from selected websites) bulletin boards on Facebook or "walls" on MySpace, talk among those suffering from chronic illness is thriving on the web and carries many advantages. It is private and confidential. No one needs to know that you are suffering or whom you choose to talk to from the privacy of your home computer. It is free. You can refine what you want to say as many times over as you wish before revealing yourself. You can choose not to answer embarrassing questions. It is safe to vent or communicate because you can be anonymous.

Figure 1. What is a social network?



Source: Helander, M.E. Mathematical Sciences Department. IBM Research, Yorktown Heights, NY.

Table 1. A dictionary of Web 2.0 applications

Application	Meaning
Social networking	Online social communities where individuals are linked together through common interests or some common theme.
Syndication, RSS feeds	<i>Really simple syndication</i> , or RSS, makes it possible for people to keep up with their favourite websites in an automated manner instead of checking them manually.
Wiki	A collaborative website that can be directly edited by anyone with access to it. One of the best-known wikis is Wikipedia.org.
Blog post	The ability for readers to leave comments (posts) in an interactive format is a hallmark of blogs.
Social bookmarking	Where users can save links from their favourite websites. Prominent examples include Connotea.org and del.icio.us.
Virtual world	Based on three-dimensional multiplayer games, this immersive experience offers a unique form of online social interaction that involves sharing various objects and creative collaboration on building and interactive services.
Ratings (voting)	Users' ratings of content, services or other users. Ratings reflect the "wisdom of the crowds" or collective intelligence regarding the rated subject or item.

for the Cancer Society, told the *Wall Street Journal* last year (Landro 2006).

At DailyStrength (www.dailystrength.org), patients and caregivers dealing with a broad array of chronic illnesses, including asthma, celiac disease and depression, can join a support community anonymously, start a wellness journal, share advice and recommend physicians, link to news stories and websites with disease information – and even send other members a virtual hug. CareCommunity (www.mycarecommunity.org) recently established a social network for caregivers facing serious illness and end-of-life-care support issues. Another example is the Wellness Community (www.thewellnesscommunity.org/), a non-profit group that provides free support and education to cancer patients and families, which last year launched a website, group loop (www.grouploop.org), to help teens with cancer connect in a private, safe environment. The group is connecting teenagers in countries around the world.

Both the American Cancer Society (www.cancer.org) and the US Centers for Disease Control and Prevention (www.cdc.gov) have been experimenting with virtual worlds such as Second Life to test whether social networks can help spread the word about such issues as nutrition awareness, cancer screening and infectious-disease prevention. "We're trying to leverage social networking for health promotion ... Everything is based on communities now," Adam Pellegrini, director of online strategy

There are many benefits that have long been associated with collaborative online support groups. Access is easy. People with mobility problems, depression, speech and hearing difficulties or caregiving responsibilities are not excluded. As Table 2 illustrates, mental illnesses figure prominently alongside physical illnesses in social networks. Anonymity encourages honesty and intimacy (White and Dorman 2001). Socio-demographic factors such as age, gender and racial or ethnic identity melt

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Table 2. Most popular MySpace communities (in top 100)*

Focus	Ranking
Depression [†]	12
Bipolar illness [†]	21
Cancer	22
Autism	30
Diabetes [†]	31
Weight loss support [†]	40
Diabetes [†]	48
Insomnia	54
Chronic pain	55
Breast cancer	60
Bipolar illness [†]	72
Weight loss support [†]	75
Obsessive compulsive disorder	79
Alcohol dependency [†]	80
Child abuse/rape survivors	91
Panic, anxiety, agoraphobia	93
Cancer [†]	94
Alcohol dependency [†]	95
Lupus	99
Deafness	100

*As of July 27, 2007.

[†]There are multiple chronic illness MySpace communities with the same or overlapping focus.

away online. Worldwide social networks are in some instances the only way that those with very rare chronic diseases can communicate with one another. The international scope of the web permits group members to draw from a wide variety of perspectives and experiences.

Social networks carry the potential to reach population groups that previously may have been difficult to reach via health education. For example, it may be that men are more attracted to social networks than face-to-face support groups for depression. Therefore, social networks augur well for the ability to reach men who would not attend live group events about depression. For Aboriginal women isolated by geography and

culture, it has been noted that social networks serve as a medium for health knowledge, support and motivation within a virtual neighbourhood (Hoffman-Goetz and Donelle 2007).

In a recent analysis of the behaviour of cancer survivors exchanging support on social networks, the most common topics in survivors' messages included treatment information and how to communicate with healthcare providers and navigate the healthcare system (Meier et al. 2007). Two large German language social networks used by patients with bipolar affective disorders were recently examined; the topics most discussed in the networks were social support services, symptoms of illness and medication. The main stated interest in participating in networks for bipolar affective disorders was to share emotions (Schielein et al. 2007). Increased interaction by participants on networks for suicidal youth has even been correlated with participants' self-ratings of reduction in suicidal intent (Winkel et al. 2005).

Web 2.0 Criticisms in Healthcare

While there are undoubtedly profound benefits to be afforded by Web 2.0 tools for those suffering from chronic illness, some valid criticisms must be acknowledged: group opinion, especially in healthcare, can be clinically misleading, or even dangerous. The poor and minorities have limited access to computers and broadband access. (Contrary to myth, elderly people use the web heavily, more so than 18- to 24-year-olds for health information [IBM Business Consulting Services 2006, March 8]). Those suffering from illiteracy may be at a particular disadvantage. Very active forums may produce such a large volume of postings that reading each message requires a considerable time commitment. Communities may also be addictive, especially where virtual friends take the place of real ones. Finally, without visual and auditory cues, online messages may be easily misinterpreted upon being read.

When examining author qualifications on sites like MySpace and Facebook, it is clear that most messages on medical topics come from people without any obvious health training and a substantial portion recommend the use of unconventional treatments (which may or may not be clinically appropriate). The problem of flawed credentials cannot, however, be said to be a fatal flaw of Web 2.0 in healthcare but rather a flaw of the information governance structures – traditionally loose systems of free association, rather than strict expert moderation. This is changing (see Giustini 2007). Ganfyd (www.ganfyd.org), a general medical wiki, stands for “get a note from your doctor” and is expert moderated, which means that only physicians approved by the editor can contribute and edit entries.

A wiki created by the Cleveland Clinic, Ask Dr Wiki (<http://askdrwiki.com>), serves as a repository of continually edited information for medical students and residents. Its goal is to create a collective memory by publishing clinical notes, images

and videos. Credentials are needed to become an editor or contributor, and its editorial policy mandates that contributors and credentials be identified.

It is anticipated that the most popular health-oriented Web 2.0 sites will ultimately be the ones carefully monitored by teams of expert clinicians.

It is important to recognize that we are only at the very early stages of Web 2.0 in healthcare, and therefore the ideal information governance models – allowing for the right level of user engagement while ensuring the accuracy of clinical information – are in development. As with public blogs on economics, where the most popular blogs on the web tend to be edited and monitored by PhD-trained economists, it is anticipated that the most popular health-oriented Web 2.0 sites will ultimately be the ones carefully monitored by teams of expert clinicians. (Kitemarking is a trustmark that certifies websites. The recommendation is usually based not so much on content [which changes] but on knowing the process and individuals behind the information production. See, for example, the EU project MedCERTAIN [MedPICS Certification and Rating of Trustworthy and Assessed Health Information on the Net], online at http://www.hon.ch/HONcode/HON_CCE_en.htm.) Leaders in healthcare social networking, such as Dmitriy Kruglyak, publisher of the Medical Blog Network (which hosts medical blogs), have called publicly for guidelines that include conflicts-of-interest disclosure and privacy protection. It is only a matter of time before such guidelines enjoy widespread adoption.

Opportunities for Hospitals and Health Regions

Hospitals and health regions enjoy an opportunity to harness the power of Web 2.0 by creating trusted communities on already existing Web 2.0 “wiki farms” or by generating their own customized Web 2.0 sites. (Wikia, at www.wikia.com, is a wiki hosting service or wiki farm. It is free of charge for readers and editors.) In this way, hospitals and regions can overlay Web 2.0 communities with their own trusted brand, make the Web 2.0 communities relevant for their clients and allied partners and impose a governance model on the community that safeguards the quality and reliability of the information contained on the site. A governance model that invites user input but imposes editorship restrictions on any clinical advice posted to the community can soften many of the criticisms of Web 2.0 cited earlier.

Consumer Health Literacy

To a health region or hospital, the potential benefits of creating a Web 2.0 presence include a more health-literate community that better understands the factors contributing to good health;

that engages actively in preventive care and self-monitoring to manage chronic illness; and that continuously learns via the website how to navigate the local healthcare system. For example, the virtual world of Second Life offers an alternative to traditional methods for educating large numbers of people rapidly about new treatments or about health dangers (such as outbreaks of *Escherichia coli*) – especially for teenagers who might not visit a government health site.

Customized wikis can advise local patients as to which social service agencies to visit for education, nutrition, counselling or rehabilitation services; or how to access telehealth services or culturally specific services. Maps – continually updated – can illustrate care paths guiding members through the maze of services for illnesses such as cancer. Once a community for Hospital 2.0 is created within a trusted, larger wiki farm such as Wikia, pages pertaining to clinical information may only be edited by designated administrators. A chief editor can select the sub-editors. People who visit the site can feel confident about clinical information that is edited by editors whose credentials are made transparent. RSS feeds can alert network members who express interest in certain topics, for example, updates on services in the local area related to human immunodeficiency virus. The network can also link to other hospitals and services in the continuum of care.

Philanthropy and Volunteer Recruitment

Web 2.0 communities offer significant advantages for fundraising and volunteer engagement. In May 2007, a social-action start-up venture, Project Agape, launched a program on Facebook called Causes in which participants create online communities to advocate for local issues, charities and non-profit organizations. In two months, the program attracted more than 2.5 million Facebook users. Using Web 2.0 tools for philanthropy is a way to connect with younger donors and new volunteers, who are the predominant user group within cause-related social networks. The American Cancer Society used Second Life last year to help raise funds for its annual Relay for Life, which attracts millions of participants in local communities who walk, donate or volunteer for the event. The cancer group has also launched a social-networking site of its own for the effort (www.relayforlife.org) and has plans to launch social-networking sites focusing on tobacco, prevention and volunteerism.

Patient Self-Care and Self-Empowerment

Web 2.0 tools can help people take charge of their own healthcare by connecting them to local services. Virtual health libraries, access to remote librarians and other health-related educational applications can also enable chronically ill patients to learn about goal-setting activities, follow-up and support services in their local area, as well as general education sessions. Web 2.0 tools offer targeted strategies to educate and activate the patient



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population, which is important if we embrace the notion that an informed, activated patient is essential to achieving meaningful population health outcomes (Barr et al. 2003).

Research and Educational Activity

The anonymity made possible by virtual communities such as Second Life can enable researchers, students and clinicians to work collaboratively to learn the needs of patients who may not want their true identity revealed. For researchers, a virtual research exchange offers a secure workplace that includes access to a wide range of information and data sources. In this environment, researchers can build and refine new clinical practice protocols and can engage in knowledge sharing or collaboration with partner organizations. Consider, for example, the Sakai Project (www.sakaiproject.org), a free service that allows educators to collaborate in research and curriculum design using rooms, wikis and real-time exchange.

Conclusion

Although a relative latecomer to the world of Web 2.0, healthcare may be the ideal practical use for this new Internet functionality. Patients surfing the web need to sift through the noise of abundant health information, much of it inaccurate, and distill the elements that will help them manage their disease and navigate their local health system. Health facilities and health systems have a role to play by building and supplementing consumer-friendly wikis and other Web 2.0 tools; in this way, they can ensure the creation of trusted information sources and stronger community bonds while working to improve population health outcomes.

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