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Jofen Han
Western Michigan University, jojofen.han@wmich.edu

Jo Wiley
Western Michigan University, jo.wiley@wmich.edu

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Digital Illness Narratives: A New Form of Health Communication

Jofen Han, Ph.D. and Jo Wiley, M.F.A.
Adjunct Faculty, Department of Business Information Systems
Haworth College of Business MS-5412
Western Michigan University
1903 W. Michigan Ave, Kalamazoo, MI 49008
jofen.han@wmich.edu
jo.wiley@wmich.edu

Abstract

Abstract: Social media has dramatically affected the way information is accessed and circulated. Social networking sites continue to create on-line communities where every participant plays an active role in seeking and sharing information. While social networks have profoundly impacted different industries in terms of communication between business-to-business and business-to-consumer interaction, they also have had significant impact on many stakeholders in the healthcare communication system. This report describes how a non-profit social networking site called CaringBridge can help patients communicate about their health challenges and gain support though their writings. When traditional "Illness Narratives" (a patient's reflective writing about his/her illness) become interactive and conversational in a digital platform, the self-expression and connectivity taking place in an on-line social community contribute immensely to the patient's health journey.

INTRODUCTION - "SOCIAL MEDIA 'LIKES' HEALTHCARE"

Today, more than 1.5 billion people around the globe have an account on a social networking site. According to a study conducted by McKinsey Global Institute, almost one in five online hours is spent on social networks—increasingly via mobile devices (Chui et. al., 2012). Undoubtedly social networking has transformed the way how information is accessed and shared, and social technologies have greatly impacted the popular culture and are being adopted across industries.

In the United States, even though there is a significant amount of debate over the use of social media in healthcare communication from manufacturers, consumers, and regulatory bodies (Popovic, Smith, & Hellebusch, 2013), social networks have continued to reshape how stakeholders in health care communicate with each other. As a physician, who uses a blog to communicate with her patients, claims, "Social media could transform health care. It's already doing it" (McCarthy, 2012, Sept. 19). Indeed, the prevailing uses of social networks in health care communication have shown that social networks have become an integral part of the health care landscape.

According to a large-scale study that examines current social network applications by health care stakeholders ("Social networks in health care: Communication, collaboration and insights," 2010), in the health care arena, social networking uses can be seen in the following areas: Maintaining health and wellness (e.g. WEGO and WebMD), disease management (e.g. PatientLikeMe and Inspire.com), clinical trial recruitment (iGUuard), Personal Health Records (e.g. PatientsLikeMe and Medhelp), Health professional training (e.g. radRounds, Sermo and Ozmosis), Public health announcements and campaigns (e.g. CDC collaborated with DailyStrength and Sermo), and treatment, physician or hospital selection (e.g. Dailystrength and FacetoFace Health). This study demonstrates that more and more hospitals and medical professionals are embracing and utilizing social media as a means to convey general health information, sometimes even personalized help (Kotenko, 2013). The Mayo Clinic, known as "the gold standard for social media in healthcare" pioneered uses of Facebook, YouTube, Twitter, and blogs (Justice, 2013, May 20). Its Facebook page has over 300,000 connections, and the blog of Sharing Mayo Clinic makes it possible for patients and employees to tell their stories about the Mayo Clinic experience. Moreover, physicians now have the opportunities to submit cases for community discussion and to better practice medicine (Seda, 2013, June 17; "Social Networks in Health Care: Communication, Collaboration and Insights," 2010). Doctors can spread good health information, address medical questions and share interesting development in the medical field. In fact,

nowadays health professionals are suggested to have a strong social media presence to establish themselves as reputable sources (Kotenko, 2013).

The benefit of using social networks also extends to the consumers. Consumers in healthcare now have places to have their voice heard. For example, some social networking sites let patients evaluate the care services provided by the hospitals they use, including clinical and nonclinical experiences. The expansive nature of social networks gives health care consumers unprecedented capacity. A patient's comments on the service he or she receives will be able to reach 14 million followers if he or she decides to "tweet it" (*Bringing the Social Media Revolution to Health Care*, 2012). Also, patients now can form on-line communities through sites like PatientsLikeMe and MedHelp, which allow participants to upload detailed information about their condition and receive information from similar patients.

In addition to disseminating and sharing information among hospitals, physicians, and consumers such as patients, providing certain types of medical services is now possible through social networks. For example, virtual sessions of online therapy offering various modules that provide anxiety and depression assistance are now available (Kotenko, 2013). A small primary care medical practice, Hello Health, has been practicing "cyber-visit" whereby patients of this clinic can IM or video chat with a particular doctor to describe their symptoms and ask the doctor for advice (Hawn, 2013). E-health, the new trend made possible by social technologies, is believed to have a significant impact on the future of U.S. health care.

However, health care industry is reported to lag behind other industries in its social network presence ("Social Networks in Healthcare: Communication, collaboration and insights," 2010). One of the major reasons may be the challenge posed by HIPAA, the Health Insurance Portability and Accountability Act. Physicians who participate in social networking avoid revealing professional and medical advice on Twitter or Facebook accounts. For example, Twitter is believed as a higher-risk environment because it basically is an open forum (Hawn, 2009; Kotenko, 2013). Also, a survey regarding consumers' trust in information retrieved from social networks reveals that health insurance plans and drug manufactures are the least-trusted sources of health information. Despite the risks and potential downsides such as consumers' lacking trust in information provided by certain types of organizations, social media tools have made the healthcare communication system flatter, more democratic, and presumably more effective (Hawn, 2009)

USERS CHARACTERISTICS

In the communication system in health care, both clinicians and consumers are using social networks. About one-third of Americans who go online to research their health are now using social networks to find fellow patients and discuss their conditions ("Social Networks in Health Care: Communication, collaboration and insights", 2010). Social media has changed online dialogue from one-to-many to many-to-many at a phenomenal speed. Who are using social networking sites for their health needs? The Health Information National Trends Study that attempted to identify the sociodemographic and health-related factors associated with current adult media users in the United States demonstrates that social media are penetrating the US population independent of education, race/ethnicity, or health care access. In 2007, among the 5,078 Internet users, 5% participated in an online support group, 7% reported blogging, and 23% used a social networking site. Statistical analysis found that younger age was the only significant predictor of blogging and social networking site participation. Moreover, younger age, poorer subjective health, and a personal cancer experience predicted support group participation (Chou et al, 2009). Another study also states that in 2010, three in four American adults were online, and over 60% turned to the Internet for health information. Research also revealed that 83% of Internet users can be classified as "e-patients," which means patients consume and share information about their health and sometimes the health of their loved ones ("Making a real impact: The CaringBridge phenomenon", 2011). What are some health-related activities health care consumers do when they use social media? A study of 1,060 users and the health-related activities they do concluded that 27% of the users commented on other' health experiences, 24% posted about health experiences, 20% join health forum or community, and 18% track and share health symptoms/behavior ("Social Media 'likes' healthcare," 2012).

USING *CaringBridge* DURING HEALTH CHALLENGES

Social media has provided a platform for one of the stakeholders of healthcare--people who get sick—to obtain and share information. Imagine a person who, after being diagnosed with a serious illness, needs to answer 40 phone calls and tells his or her situation 40 times to people who show their concerns. Instead of making or being overwhelmed with many phone calls or e-mails, now one can use CaringBridge or some similar sites like CarePages to save a lot of time and energy, and especially ease a family's communication burden when encountering a health challenge. CaringBridge is a non-profit web-based service that helps the families of people who have suffered a medical crisis set up a simple website and blog to keep friends informed and updated. In 1997, to help a friend cope with a life-threatening pregnancy, Sona Mehring, a software programmer, designed a website that not only kept family and friends updated but also allowed them to post words of encouragement. Today, the first single webpage of CaringBridge organization has grown considerably to over 3 million members, logging with half a billion website visits and 13 million messages (Clemence, 2008). Over 1,800 hospitals and healthcare facilities partner with CaringBridge and recommend the service to their patients ("Top hospitals go beyond patient outcomes to improve patient satisfaction," 2011).

Social media undoubtedly changes the nature of interaction among participants. It consists of four unique characteristics: user generated content, community, rapid distribution, and open, two-way dialogue ("Social media 'likes' healthcare", 2012). CaringBridge exemplifies all these four characteristics. The patient/user generated content has become a platform for patients to write about their health and feelings, thus making their journey easier, and the two-way dialogue through visitors' signing the guestbook builds an online social community that connects people in authentic and meaningful ways.

The creators of CaringBridge personal sites more often are not the patients themselves; sites are set up by caregivers giving updates and speaking on behalf of the patients. Nevertheless, when a patient starts writing about her own experience, the CaringBridge's blog setting has become a great way for a patient to "capture the health journey" ("Will facebook replaces CaringBridge and CarePages," 2013).   Due to its blog or journal writing format, CaringBridge is different from Facebook, which, as Mehring argues, is "for small talk" whereas CaringBridge is "where you go when you want to have a conversation"(Crosby, 2011). It is also more protective and provides value to everyone involved—the patient, the caregiver, the circle of family and friends. The ability to express oneself through writing and the opportunities to connect with people have made CaringBridge a "value-added" personal health social network ("Top Hospital go beyond patient outcomes to improve patient satisfaction," 2011).

Many testimonials from caregivers who set up a CaringBridge site mention that Caringbridge has been a lifeline between family and friends during the time when a loved one gets sick (Mehring, 2013). Numerous users/writers who use the CaringBridge journal/blog to write about their health experiences claim that writing itself is therapeutic. As one user testified, "posting in the journal became efficient, not to mention more than just writing. It was therapy" (Mehring, 2013, p. 32).

ILLNESS NARRATIVES

The time-honored research on the therapeutic nature of writing about one's illness including psychologically traumatic experiences proves that self-expressive writing has a profound effect on a patient's emotional and physical health and well-being (Pennebaker, 1990; DeSalvo, 1999; Adams, 1999; Hunt, 2000; Grason, 2005). DeSalvo (1999) and Hunt (2000) have called writings about one's physical sickness "the Wounded Body Narrative" and "Illness Narratives" respectively. In today's persuasively digital environment, the journal writing a patient takes initiative to compose through CaringBridge allows the patient to post his or her "Illness Narrative" and deal with an ongoing illness in a new way. Following is a current and ongoing case that illustrates how a site user of CaringBridge can share her experience, voice, insight, and obtain support from friends during her medical journey

Iris (name changed) was diagnosed a type of stage IV cancer two weeks before her 49-year-old birthday. The diagnosis, of course, came as a shock. In her "story" page (a synopsis of a patient's situation when he or she sets up the site), Iris wrote," From having a little pain on the lower abdomen to the diagnosis of stage 4 (type of cancer omitted) cancer, I had received one bad news after another within a short period of time. However, I have experienced the peace beyond understanding." Iris belongs to the group of CaringBridge site authors who "tend to

be significantly active in social media activities than the average individual" ("Making a real impact: the CaringBridge phenomenon", 2011). The average age of adult social networking site users has increased to 38 in 2010 from 33 in 2008 ("Top hospitals go beyond patient outcomes to improve patient satisfaction," 2011). Iris is competent in using social media. She has both Facebook and Google plus presence and is comfortable with creating social media content such as uploading video or music. After her first chemotherapy, Iris set up the site and has been journaling weekly to update her health situation.

Narrative, according to Garro and Mattingly (2000), is a fundamental human way of giving meaning to experience. Research has demonstrated that journaling helps people who have physical illness create "a literature of their own" (Broyard, 1992) to articulate the experience, make sense of it, and eventually gain and share insights (DeSalvo, 1999). Audre Lorde (1980), author of *The Cancer Journal*, explained that she used her diary to give her illness voice. Each entry of Iris' journal/blog was given a title and focused on one event and the insights she got from the event. In her fifth journal entry written after the third chemotherapy, Iris wrote, "Since I was diagnosed with cancer, my perspective on suffering has changed little by little. . . . The question for me becomes [this]: are the "bad things" God allowed to happen to me really bad?" In the tenth entry titled "Who Needs That Hair Brush," Iris used humor to mention implicitly her apprehension of losing her hair in the near future: "Yesterday I went to s nursing home to visit a friend's husband . . . .Before we walked out his room, my friend's husband took out a hair brush from his pocket and said, "I don't need this" and showed me his bald head with a boyish smile on the face. We met at church a couple times before, but he did not remember me at all. I said jokingly: "Well, I won't need hair brush for long, either" and gave him a wink. My friend explained to him that I have cancer and am under chemotherapy. He said nothing but gave me a big, warm hug. Although he has lost some of his memories, he has not lost his nice personality. It is worth pondering on. . . ."

At the end of this journal entry, Iris expressed her gratitude and stated, "I don't know which one is worse—my cancer or his Alzheimer. But I know God gave all kinds of blessings if we are going to count them." Indeed the theme of counting blessings and accepting the reality of having cancer can be found in almost every entry of Iris' online journal/blog.

Digital journaling has provided a new kind of writing space where writers can create words, images, and sound. Iris' digital journal is multimodal. Oftentimes Iris uploaded a song from YouTube at the end of her journal entries. With readers in her mind, Iris intended to share the song and to encourage her readers, the site visitors.

Digital writing reaps the value of being able to make personal connections that traditional published narrative might not accomplish. In contrast to the traditional publishing mindset, narratives posted through social networking sites are framed in a social communication model, which means the writing becomes interactive and conversational, and usually open to all who wishes to participate (DeVoss, Eidman-Aadahl, & Hicks, 2010). In other words, audience members are no longer passive recipients of messages but active participants in a conversation (Lambert, 2012).

Illness narratives posted onto a social networking site creates connectivity needed by a patient who seeks to articulate and make sense of his or her health experience. According to research and medical authorities, "the most significant impact comes from personally connecting with others" ("Making a real impact: the CaringBridge phenomenon", 2011). Connecting with someone during times of crisis or joy offers real health benefits. Visitors of a CaringBridge site can either have open access or they may be required to registered and use a password to log in. A ticker that counts visitors appears on the upper right corner of the site's homepage. Many authors of CaringBridge sites praise the support they get from people who sign the guestbook and really think it is a lifesaver (Muhering, 2013). "I treat my journal as a conversation between me and my friends, and it kept me going," stated by one of the CaringBridge users (Clancy, 2013, p. 61).

The social networking sites such as CaringBridge takes science and technology and mixes it with two fundamental human needs: communication and relationships (McCarthy, 2013 April 19). When a CaringBridge site is created, the site author make up a list of recipients, and e-mail notifications are sent to the recipients. Each time a new entry is generated, the recipients are notified through e-mails. The recipients, the intended and invited audience, can then choose to sign the guestbook where they can leave comments or converse with the site author. The author and any recipient can also click a "like this" link to show his or her appreciation of each entry in the guestbook. At the end of August, 2013, two months from its inception, Iris' CaringBridge site has generated 13 journal entries and 331 visits. The outpouring of love shown through words of consolation and encouragement in the guestbook was

amazing. The interactive and conversational feature provided by social networking sites such as CaringBridge gives patients a platform to receive love and to be loved (Karpen, 2013).

In our networked world, the Internet, social media posts, and check-ins are a way of life. Research on social networks continues to demonstrate how social technologies create an immense amount of economic value and productivity among industries. However, social technologies can also provide individuals with significant non-economic benefits. This non-economic power stems from the innate appeal of self expression and social interaction. Users are empowered by having the pleasure and intellectual stimulation that people derive from sharing what they know, expressing opinions, and learning what others know and think (Chui et al, 2012). As demonstrated in Iris' story, a personal health social networking site such as CaringBridge--where a patient chooses to "publish" his or her illness narrative--contributes to health communication and a patient's health journey.

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