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What is This?

Communication online with fellow cancer patients: Writing to be remembered, gain strength, and find survivors

Yu-Chan Chiu[1] and Yu-Ling Hsieh[2]

Abstract
This qualitative research explored how cancer patients' writing and reading on the Internet play a role in their illness experience. Focus-group interviews were conducted, with 34 cancer patients participating. A grounded qualitative analysis method was applied to analyze the interview transcripts. The results show that by writing personal blogs, cancer patients reconstructed their life story, expressed their closure of life, and expected to be remembered after death. Reading fellow cancer patients' stories online significantly influenced cancer patients' perceptions and expectations of their own illness prognosis, and that influence was sometimes greater than that of the doctors' influence.

Keywords
cancer, communication, coping, Internet, qualitative methods

Introduction

The Internet has become a major source of information for the public. People frequently search for health information online, particularly materials related to their diseases (Anderson et al., 2003; Berland et al., 2001; Bylund et al., 2009; Chen and Siu, 2001; Murray et al., 2003; Pemberton and Goldblatt, 1998). In Taiwan, where this study was conducted, 50 percent to 73 percent of people frequently use the Internet (FIND Institute for Information Industry, 2010; Hsu, 2005). Among the Internet users, 50 percent to 92 percent have searched for health information (Chuech, 2001; Hsu, 2005; Tseng and Chang, 1998). Moreover, past studies have indicated that for patients, using the Internet as a source of information increases their medical knowledge, gives them a greater feeling of control in medical decisions, and also empowers them to discuss such decisions with doctors (Anderson et al., 2003; Berland et al., 2001; Bylund et al., 2009; Chen and Siu, 2001; Chiu, 2011; Murray et al., 2003; Pemberton and Goldblatt, 1998; Ziebland et al., 2004).

However, the Internet is not just an information source. More importantly, it is also a

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communication medium by which patients actively deliver information, exchange opinions, and discuss their illnesses with fellow patients who have similar diseases. Therefore, instead of viewing the Internet only as an information source, this study aimed to explore the role of the Internet as a communication medium in the illness experience of cancer patients.

Writing on the Internet

One of the most common ways of conveying information on the Internet is to keep a blog for writing personal stories. People use personal blogs to express their own stories, feelings, and thoughts. For example, cancer patients may use a blog to keep a journal about the progress of their disease, their experiences, and their interests and daily life (Cheung, 2004). Writing on the Internet can have personal meaning for patients in several ways. By illustrating their illness, patients attempt to create continuity with their biography (Hardey, 2002). In particular, when people share their own stories on the Internet, they exchange experiences with fellow sufferers. They also seek self-reassurance, legitimization, and validation that their own story has been correctly constructed. In doing so, they work on their self-formation (Orgad, 2004).

For patients with life-threatening diseases, such as cancer, the Internet may also be a means of expressing closure (Stanton and Danoff-burg, 2009). By writing on the Internet and delivering their personal stories, patients work on reconstructing their own life stories and share them with readers online. Such writing allows patients to focus on their lives not as a finite quantity that is running out, but as something to be lived, and thus helps them to avoid feelings of helplessness and hopelessness (Giddens, 1991). Writing is also a means of leverage out of social isolation and into a community of equals (Høybye et al., 2005). Moreover, telling personal stories and disclosing emotions in writing could have a positive effect on cancer patients' health outcomes (Høybye et al., 2005).

Reading and sharing fellow patients' stories online

Online, in addition to writing their own stories, patients may also frequently read and respond to those of fellow patients (Kivits, 2006). The information offered by other patients may have as much or more influence on patients than that from physicians. One study indicated that patients rely on a variety of web sites and that general and lay health information sources are as respected as medical ones (Kivits, 2006). Patients value information that is individualized and applied to their personal experience (Reeves, 2001). For example, patients feel that information related to living with cancer, including how to handle the side effects of treatments, how to talk to family and friends, how to cope, and even how to make treatment decisions, is best provided by other patients who have similar cancer experiences (Balka et al., 2010).

In the present era of electronic communication, exchanging information by communicating and interacting with others on the Internet has become an important part of patients' illness experience. The suggestions and opinions shared online by patients who have never met have an important influence on them. Whether the patients are browsing or actively participating, being able to read and share other people's experiences is indeed a significant feature of the Internet as a medium and a source of health information (Burrows et al., 2000; Orgad, 2004).

Past studies have indicated that interacting with others in Internet support groups increases patients' medical knowledge, empowers them to make medical decisions, provides them social support, and helps them find ways of living with cancer (Balka et al., 2010; Høybye et al., 2005; Rodgers and Chen, 2005; Sullivan, 2003; Wen et al., 2011). Most of these studies have focused on single online social discussion groups, and various methods have been used to collect data, such as online interviews, e-mail exchanges, or analysis of posted messages.

However, cancer patients may not join and post in only a single support group. Instead, they may post information in several groups while also writing their own blogs.

Therefore, this study aimed to understand how the Internet, as a communication medium for delivering, receiving, and exchanging information, is part of patients' illness experiences. We thought that instead of interviewing people within a particular support group or analyzing posted messages, it might be better to interview patients to explore their reasons for writing and sharing information and to ask what that means to them. This study focused on two research questions: why cancer patients write on the Internet, including their blogs and sites such as support groups, and how such writing and the reading of other patients' messages impact their cancer experiences.

Methods

Data collection and participants

We used focus-group interviews to understand what motivates cancer patients to write on the Internet and how their online interactions with fellow patients have influenced their illness experience. We used the focus-group interview instead of individual in-depth interviews because we think that group discussions can inspire participants who have similar experiences of using the Internet and a greater range of ideas on discussion topics (Hennink, 2007). Therefore, by collecting information from group discussions, we could obtain more wide-ranging experiences and perspectives.

To recruit participants, we posted invitations on Internet web sites related to cancer, including several cancer patients' blogs, support groups, and organizations. We also contacted several non-governmental organizations (NGOs) related to cancer and posted recruiting information on their office bulletin boards. The recruitment criterion was cancer patients or family members (caregivers) who had the experience of posting,

searching for, and reading information on the Internet.

Cancer patients or caregivers who were interested in participating in this study contacted the research team by e-mail or phone. Based on their availability, we assigned them into one of the discussion groups. Overall, seven focus-group discussions were held, and a total of 34 cancer patients and 12 caregivers participated in the discussions. However, we found that the motivations and expectations of caregivers who used the Internet differed from those of the patients. Since it would not be appropriate to blend their experiences together, in this article, we present only information on cancer patients.

The majority of patients participating in this study were female (61.8%), over 40 years old (55.8%), and college graduates (52.9%). Most (70.6%) participants had been diagnosed with cancer within the past 1–5 years, and 76.5 percent were in stable condition and regularly following up on treatments. Most participants were diagnosed with respiratory or circulation system cancers (38.2%) or female reproduction cancers (29.4%).

Each focus-group discussion took 2–4 hours and was digitally recorded. At the beginning of the discussion, the moderator introduced herself and informed the participants of the research goals and their rights in this study. The group interviews began with each participant describing his/her illness experience and how using the Internet had played a role in their illness experience. The general discussion, led by the moderator according to the interview guide, included what and why they wrote on the Internet and how their illness experience was influenced by writing their own stories and reading those of other patients online. Each group included participants of various ages with different types of cancer and of both genders. Although some groups were more enthusiastic than others in discussions, we did not find that the themes that emerged differed among groups. All discussions were transcribed verbatim.

Analysis

We used a grounded approach to analyze what themes emerged regarding the conveying of information and reading of other cancer patients' stories on the Internet. The grounded and inductive analysis approach allows researchers to discover frequent and significant themes regarding research questions emerging from the raw data (Thomas, 2006). The analysis process included several steps. Initially, with the research questions in mind, three coders, including the authors, read transcripts independently and then met once a week to discuss one interview transcript at a time. At those meetings, we discussed and shared our perspectives on what themes emerged from the transcript, possible further coding schemes and codes, and possible explanations and theories. After all the transcripts were discussed, the codes were developed. The three coders then independently coded portions of the transcripts, but weekly meetings continued for the coders to discuss any issues related to coding. The major themes that emerged and were coded in this study include what the writing on the Internet means for cancer patients and how reading others' stories influences cancer patients. Other themes that emerged and were coded, but are not represented here, were how to evaluate information on the Internet and how that information influences doctor–patient communication.

Results

By writing on the Internet or communicating with fellow sufferers through the Internet, participants have found ways to confront themselves and their diseases. Moreover, even simply posting an illness diary on the web empowers participants for self-formation. Below, by quoting some participants, we show how the Internet, as a communication medium for expressing oneself and interacting with others, has played a role in supporting these people who are living with cancer and has added new aspects to their experience of the illness. The results include two parts. First, we explore what motivates cancer patients to post information on the Internet and what that means to them; second, we show how participants were influenced by their own writing and by reading other patients' stories on the web.

To be remembered after death

One of the important motivations for cancer patients starting to write on the Internet is that they believe it is the place where they can be known and remembered. Many interviewees talked about how they wanted to leave something behind after they died and how the Internet was an appropriate platform for them, one where the information they had posted would remain for a long time. Several interviewees declared that their reason for writing a blog was particularly to leave something for their children to remember them by. Some wanted to preserve their contributions for their fellow patients to see online so that they could contribute even after death:

> My blog is going to be left for my children. I want to organize my favorite music, photos and other things and want my children know that at least their mother left these for them.

The above patient views her blog as her biography. She continues to write and arrange the content for people to remember her.

> I started a blog. Now I know that someday, even after I have left this world, something will still be there.

> Actually, people like us who have this kind of illness experience [cancer] would think of leaving something in the world. Writing a blog is a way to maintain our influence after we are no longer in this world.

These two patients expressed that they had thought about death; writing their blog was a way to confront death and continue their lives. Writing on the Internet might help patients face the uncertainty of their disease prognosis and prepare for, especially psychologically, the possible inevitability of the end of life.

Writing for relief and gaining strength

Conveying information on the Internet also helps patients to release their negative emotions. Writing on the Internet is an important channel for them to disclose their frustrations and feelings of helplessness. When patients face a difficult situation, whether it is physical, psychological, social, or even involving medical care, the Internet is a place where they can vent their frustrations.

> During the chemotherapy treatment course, I had many fights with my family. During that time, I was not getting along with them. But I forced myself to keep writing something on the Internet, and that helped me past the hard time.

> Actually, my writing is bad. I started a blog and I wrote it slowly but kept writing it. I just wanted to relieve my pain and loneliness.

The above two examples indicate that the Internet plays an important role as a communication platform in relieving the distress of the patients and gives them strength to survive. Cancer patients' negative emotions sometimes are associated with the frustrating medical care situation, such as dissatisfaction with their own doctors. By writing about their feelings of helplessness on the Internet, patients maintain harmony in their relationships with their doctors. One participant said that sometimes she was not satisfied with her doctor's short answers to questions about her situation and treatment. Since she did not want to have a conflict with her doctor face-to-face, she complained about her doctor on her blog.

Writing for their fellow patients

Some people hope that by posting their illness stories and experiences on the web, they can help fellow sufferers:

> I am very optimistic … So I hope other people can be infected by my optimistic attitude. That's why I write a blog.

> I post the medical information and experience that I have learned on my blog because I think many cancer patients might, like me, not have had much knowledge at the time we were diagnosed and don't know the medical terms. Therefore, I post the relevant information I find, for people's reference, so that people can increase their knowledge.

These patients' blogs provide a platform for exchanging information among people with the same disease. In addition to keeping illness diaries on the web or writing to share their experiences with others, participants also read fellow patients' stories and are influenced by them.

The influence of fellow patients

Sometimes, fellow patients affect the patients more than their own doctors do because patients believe that the information from their online peers might have greater credibility than doctors.

> The words patients say to each other have a great power. For example, when my doctor told me some information, at first I was dubious about it. However, when some patients online said the same thing that my doctor had said, I immediately believed them.

The above excerpt indicates that patients' experiences and suggestions could have strong influences on others. Fellow sufferers who have similar experiences have great credibility with the patients.

> My doctor told me there is a new medication we can try. Someone online told me that the side effects of the medication are the smallest among all the options. This information gave me confidence for my decision to change medication.

The above extracts illustrate that information provided by other patients on the Internet has a powerful influence on patient's decisions.

> I believe whatever information I see on the blog "Fight for cancer." I believe everything submitted

by people who have gone through cancer. I really do.

I really think the information provided by fellow patients is real because I think they would speak from the heart. Their personal experiences are better than lots of statistics provided by doctors.

These two patients strongly declared their complete trust in fellow patients on the Internet, even though they had never met them.

Finding survivors

Facing the life-threatening disease, patients feel afraid and alone while fighting for survival. However, by reading fellow sufferers' stories on the web, cancer patients can gain confidence to fight the disease. Bloggers who have survived the disease and are living well may serve as role models for the readers.

I go to check how long people have been sick. If he is still alive now, I could also be alive [after that long]. Actually, we all have this kind of thought. He has lived for more than a decade since being diagnosed. I could do this too.

If I see another person had the same cancer as me and he was cured, I feel encouraged. Or if he has experienced pain and serious side effects of medication as I do right now, all of these give me strength.

However, sometimes, patients learn about other patients' worst experiences or situations. Instead of discouraging them, such input helps them prepare mentally for difficult times ahead.

You can also learn what could be the worst situation from other patients' experiences, and if my situation is better, I feel I'm lucky.

A sense of belonging

Reading other patients' stories on the Internet can give patients the strength to live with cancer. Through interacting with others on the Internet, many patients get social support from other cancer patients' encouragement and experiences.

Sometimes, I go to cancer patients' blogs and find that I am not alone. I feel like I still have friends.

This patient articulated his feelings of loneliness and isolation in real life; however, by interacting with other patients on the Internet, he found a sense of belonging that supported him while he fought the cancer.

Discussion

This study found that the Internet serves as a platform for patients to write about their illness and that it has helped them in many ways. In particular, the Internet is a place where cancer patients create content for their family and friends to remember them after their deaths. In the age of Web 2.0, with low technological barriers, patients can easily generate content for the ones they love and maintain their relationships. More importantly, writing on the Internet allows patients to deal with and think of possible arrangements as they approach the ends of their lives. Writing, planning, and arranging things ahead of their deaths might help patients face and mentally prepare for the future. Indeed, patients who face death have a need to express their own and others' reactions to their illness (Bingley et al., 2006).

The sharing of "the personal experience of dying and facing death through narrative would appear to provide therapeutic benefits that prove supportive for the patient, their family and friends" (Bingley et al., 2006). Therefore, the Internet, especially personal blogs, is an important medium of intrapersonal and interpersonal communication for cancer patients to communicate with themselves and with family about the meaning of their lives.

Perceiving that death might come in the near future, cancer patients intentionally write on the Internet to reflect on their lives, keep diaries, and express feelings about their illnesses. Cancer patients might use the Internet as a

medium for self-expression, self-exploration, and self-construction (Cheung, 2004; Döring, 2002; Pennebaker, 1997). For some participants, web pages are a form of communication comparable to other texts, such as life stories, letters, and diaries. However, it is the potential mass of readers of home pages that make them distinctly different from traditional forms of self-representation (Hardey, 2002). Therefore, patients' personal blogs may serve two purposes: one is for reconstructing their lives for themselves and the other is for connecting with family and friends. Both goals are important and meaningful for patients in expressing closure. The altruistic motive is also important for patients who write on the Internet; they can share their experiences and give support to their fellow patients.

While writing on the web is important for cancer patients constructing their identities, reading and interacting with others online also affect their sense of self in significant ways (Orgad, 2004). This study found that cancer patients are significantly influenced by their fellow patients online, consciously or subconsciously. They tend to compare their conditions with those of fellow patients online. Patients tend to be interested in fellow patients' experiences with coping with emotions, the impact of cancer on daily life, and physical discomforts (Overberg et al., 2007). The patients in this study were insecure and worried about the unpredictable future; they strongly desired information, and the online peers' experiences were valued as the most important reference.

Furthermore, several participants expressed that they would intentionally search for information on how long their peers had survived and what they had encountered, and then they would compare their conditions with those of their online peers. Cancer patients have a need for social comparison, a sense of camaraderie, and solidarity. "Seeing others coping well can provide confidence and reassurance, while downward comparison with those who are physically worse off can make people feel better about their own situation" (Locock and Brown, 2010).

We also found that the influence of fellow patients on a patient is greater than that of their own doctors. Patients might make a medical decision because of the recommendations of some "online friend" whom they have never met. Experienced fellow patients sometimes play a role in enhancing cancer patients' choices when they are uncertain about their decisions. In the past, without the Internet, patients might not have easily learnt of the existence of fellow patients, not to mention exchange information with them. However, with the Internet, particularly in the age of Web 2.0, patients easily share and learn about each other's perspectives and experiences of illness and treatment. Therefore, the influence of fellow patients on the patient's illness experience is amplified. The results of this study might reveal some aspects of that influence; however, more studies need to explore this matter further.

Although it is common for cancer patients to continuously exchange information on the Internet, not many studies have explored why patients write on the web or how doing so affects and becomes part of their illness experience. The results of this study fill that gap to some extent. Unlike keeping a handwritten diary for only the writer to read, writing on the web not only involves expressing and exploring oneself, but, more importantly, also brings in other readers to share their thoughts and exchange personal experiences and stories, which are more valuable and significant than information seeking (King and Moreggi, 1998).

Overall, the Internet, as a communication medium for cancer patients, helps them cope with cancer. However, writing and exchanging information on the Internet could also have negative effects on patients. They might obtain potentially harmful medical information, and some information could cause negative psychological consequences (Shaw et al., 2008; Walji et al., 2004). For example, one of the participants in our study articulated that she completely trusted whatever cancer patients said on the Internet. If the information is incorrect, such trust could be dangerous.

In this study, we did not find that participants expressed any negative effects of the Internet, although one participant did mention that she tended to avoid upsetting information related to others' bad personal experiences or health outcomes. Two possible explanations could account for why we did not find any harmful effects of the Internet. One is that these participants had suffered no negative effects, and the other is that during the focus-group discussions, participants may not have found it easy to express the negative effects without an appropriate context. Future research could investigate this issue further.

Based on the results of this study, it is suggested that health professionals help or encourage newly diagnosed cancer patients to write and interact with other patients on the Internet to assist them in coping with their illness and acquire social support (Elwell et al., 2011; Lieberman and Goldstein, 2005). Due to the Internet's potentially deleterious effects, it could be important for health professionals to tailor services or develop user-oriented web sites to help patients to evaluate online information (Elwell et al., 2011; Zimmerman et al., 2003). This study has several limitations that need to be acknowledged. The results of this study cannot be generalized to those who have limited access to the Internet or are not Internet users, such as people living in rural areas, the poor, and the elderly. The majority of participants in this study were female, middle aged, and college graduates; therefore, the results of this study also may not apply to other populations of Internet users.

The results of this study indicate that by writing personal experiences on the Internet, cancer patients reconstructed their life story, articulated their closure of life, and hoped to be remembered after death. In addition, reading fellow patients' stories online substantially affected cancer patients' perceptions and expectations of their own illness prognosis, and that influence was sometimes greater than that of doctors.

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