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"To tell or not to tell?": Incorporating Disclosure and Privacy Requirements in Web Portal Design for Malaysian Cancer Patients

Nasriah Zakaria

Universiti Sains Malaysia, Penang MALAYSIA

Abstract

Cancer patients need to disclose their health information to their disclosure network: a group of people who patients disclose sensitive health information. The disclosure process can be done using oral as well as communication technologies like telephone and the Internet. In this paper, I propose a research agenda to ***get requirements from cancer patients and their disclosure network to build a web portal for cancer information management.*** *A web portal is conceptualized as a website set up by healthcare providers whereby patients have the ability to import necessary information (monitored and verified by healthcare providers) from their electronic medical record to disclose information to their disclosure network. Patients need to make active decision who and when to disclose as well the depth and level of information to share with others. This paper will outline the importance of the research, the methodology and expected outcomes from this research.*

Keywords:

Web Portal, disclosure, privacy, cancer information

Introduction: Health disclosure

Self-disclosure is defined as "any message about self that one communicates to another" [6]. In this paper, I will use the term self-disclosure and disclosure interchangbly. The topic has attracted scholars from diverse fields – communications, information studies, social psychology, sociology, and psychology. Northouse and Northouse (1998) presented five variables in health communication, where disclosure is one of the central variables that determine the effectiveness of communication. The authors discussed disclosure as a variable since the presence (or absence) of disclosure facilitates (or impedes) effective health communication among patients and medical teams.

Numerous studies have examined disclosure of health information. These studies looked at the content, frequency and consequences of self-disclosure in different medical situations and raised different issues of disclosure, but frequently ignored the balance between disclosure and privacy issues (Cozby, 1973; 17]. Wiener et al. (1996) explored the process of disclosure and consequences among HIV patients and their support network. It examined the caregiver-patient dyad it did not discriminate between the different roles of caregivers during the coping period, thus we are unable to conclude what specific roles are crucial for effective communication with the dyad. Another study [1] explored how family and caregivers cope with cerebral palsy, and found that support network members were dissatisfied with the information disclosure activities. That study also determined that factors such as the age of the child, the timing of diagnosis and the severity of physical disability influenced information disclosure. At the end, the study suggested "best practice" guidelines for disclosing the diagnosis of an illness to the support network. Contro et al. (2002) showed that some family members such as siblings were often not included during the information disclosure process; this in turn caused the siblings to feel "left out" of the coping process.

A few studies pointed out the lack of empirical work in understanding self-disclosure among medical teams and family in chronic illness situations [2, 5]. Families also made it clear that they wanted more information from the medical teams in order to be able to provide the appropriate support for the patient [2,9]. Other recent research on self-disclosure in healthcare examined different situations, contexts and issues as well as the nature of relationships. Topics examined include the process of disclosure (e.g. content and frequency) and its consequences [9], the dyad relationship during disclosure[14,22], practices for disclosing illness [1], disclosure of chronic illnesses [2,5] functional perspectives on health disclosure [7], privacy and disclosure [21], and the influence of illness, relationship and information-seeking on disclosure [4]. Recently, self-disclosure research in healthcare has begun to pay attention to the larger group of people involved in patient care – friends, employers, spiritual groups and self-help groups. Petronio and her colleagues (2004) explored the role of these "informal advocates" by examining the self-disclosure behavior of family and friends when they were present during a patient's visits with the physician and/or medical team.

All the empirical work mentioned above informs the question of self-disclosure in various medical situations. However, it is clear that little work has been done on the disclosure of health information using Information and Communication Technology (ICT) , specifically using web portal. Thus it is a good candidate for exploration using grounded theory, when little is known about a topic.

ICT for health disclosure

There are numerous of health websites resided in the World Wide Web today. Most of them provide health information on specific illness, treatment, drugs and rehabilitation. Websites like WEBMD (http://www.webmd.com/) and Ask Dr. Greene (http://www.drgreene.com/) are moderated by healthcare professionals and they are endorsed as one of the most reliable and trustworthy health websites. There are also many social support type websites that provide emotional support and information sharing among patients and family members. In addition, there are also new research developments for health web portal. There are many different elements that go into the web portal. For an example, a group of researcher designed and developed a diabetes web portal where patients are able to import "diabetes care plan" from their electronic medical record. Patients were able to use this information from the portal to make decisions on their own diabetes care management [8].

The focus of this research is to explore the possibility of using health web portal for health communication. The web portal has to have the ability to import medical record so that patients can use the technology to disclose information to others. The uniqueness of this research is to explore the disclosure and privacy requirements for the web portal design.

The Malaysian Government, under the Multimedia Supercorridor (MSC), has invested billions in ICT infrastructure to support Telehealth (http://www.telehealth.com.my/portals/myhealth/) projects around of the country. One of the main projects is to develop a website called Telehealth to provide credible and trustworthy health information in Malaysia context. The mission of the web portal is to enhance the quality of health among Malaysians. However, there is no cancer-specific web portal has been developed for patient communication. Thus, the outcome of this research can merge with the existing initiatives in MSC.

Methods

There are two stages for this research; the first one is to get the requirements on disclosure and privacy from patients. The technique proposed in this stage is using face to face interviews and grounded theory analysis. In the second stage, I propose to conduct software prototyping to evaluate the usability of such portal. This involves the development of desired prototype and a think aloud technique to capture user satisfaction on using the prototype.

Stage 1: Interview with patients

An interview is defined as a construction of knowledge [10] or as a "purposeful conversation, usually between two people but sometimes involving more" [13, page 93]. "Purposeful conversation" here means that interviewers have chosen a specific topic that both interviewer and interviewee can explore and discuss at length. An interview is a tool with which to elicit information from a participant, to find out his or her perceptions, meanings and construct of reality [16]; its purpose is to gather what people say about their perceptions, feelings and behaviors.; its purpose is to gather what people say about their perceptions, feelings and behaviors.

As part of my preparation, I reviewed literature pertaining to conducting interviews. From several previous research projects, I had prior experience conducting interviews with patients, family members and medical personnel in a hospital setting as well as with undergraduate students and these experiences enhanced my confidence in my ability to conduct interview-based research.

This study employed face-to-face semi-structured interviews. Interviews will be conducted wherever the subject feels comfortable. With the subject's permission, I will record the interview session using an audiotape recorder. If respondent refuse to be taped, I will take notes during the interview.

Interview protocol

I have developed an interview protocol to start up interviews with cancer patients. I designed a protocol with a background question that asks patient's disclosure behavior when dealing with cancer. Then, I created some questions to elicit the requirements for the future web portal (Figure 1). These questions will be modified based on the feedback by the subjects.

Sampling

Research subjects comprised of medical patients in Malaysia. I will select patient with any types of cancer illness. I chose cancer illness because it is one of the leading illness in Malaysia [11]. The annual incidence of cancer was 30,000 in the year of 2000. Cancer illness has a predictable prognosis where patients have some flexibility in planning either their treatment, recovery or facing end of life situations. With this existing factual in Malaysia, it is appropriate to explore how to build a cancer specific web portal for cancer patients and their disclosure network.

Research subjects will be selected using a convenient snowball-sampling technique. The technique is convenient in the sense that respondents are recruited based on whoever who meet the criteria and was available for the interview. Using the snowball sampling technique, I will identify research volunteers based on others' recommendations [3]. Many patients who would have been reluctant to discuss their illness with a stranger were more open and willing to talk when approached by someone with whom they were comfortable. A snowball-sampling technique

takes advantage of the natural human tendency to extend trust through social relationships, since the interviewer is implicitly endorsed as trustworthy by the participant who provides the referral.

Introductory questions
What I'd like you to do today, if you can, is to tell me **the story of how your family, friends (and others) found out about what was happening with you**. I'm going to make a few notes and draw a couple of diagrams as we go, if you don't mind. Could you begin by telling me – when you first found out about your condition – who did you tell first and what did you tell them?

-How did you decide to tell her (him)?
-What made you decide to not tell her (him)?
-Why did you decide to wait to tell her (him)?
-What was the next big piece of news you got from your doctors?

The next set of question focus on the use of web portal to disclose health information.

If your hospital had a system where you could make a list of people to whom the hospital could release information about you, who would you put on that list? What kind of information would you want them to get?

-What kind of system (Web based, Phone messages, Text messages) do you prefer to use?
-Describe the user interface that you prefer
- Tell me what kind of privacy and disclosure concerns you have for the system?

Figure 1 - Interview Protocol

Data analysis

Grounded Theory is a qualitative data analysis technique that serves several purposes [20, page 24]: immersion in the real world situation to gain a deeper understanding of the research phenomena, formation of a theoretical framework that arises from the data itself, and comprehension of the process of change in real situations.

Analysis and coding will begin as soon as the first interview ends and continues until the last interview is completed and coded. Grounded theory recommends that data analysis take place in parallel with data collection [12] so that the researcher is able to make ongoing adjustments to the existing data collection process. For example, analysis of subjects' responses in the first few interviews may suggest new dimensions and directions for subsequent interviews. Ongoing data analysis in parallel with data collection also encourages the early discovery of new insights rather than waiting until the end of the entire data collection process.

Stage 2 study

In the second phase, the main research goal is to expose users to a web portal prototype and to evaluate user acceptance. The focus will be on user interface for the portal where I will explore factors that influence patient to use web portal to disclose sensitive information. Since there is no specific web portal exists yet for patient to communicate and disclose sensitive information with their disclosure network, I would like to employ a socio-engineering approach. With this approach, I will develop a software prototype and refine the design iteratively by incorporating end user needs at every stage. An adaptation of a software engineering approach called rapid software prototyping [19] will be applied to my socio-engineering nature of work.

In creating a "universal" web portal that could be used by patients all over the world, no single theory that can inform the best web portal design for disclosure activities. This is because there are many technological, human, situational and institutional factors that could influence the final product. It is a very complex design and development process to create a "one for all" system, thus a qualitative combined with rapid software prototyping approach seem to be most suitable way to proceed. In this optimization approach, researcher will try to maximize the user acceptance into system design and development. The end goal of this research is to develop an appropriate ICT innovation that could enhance social interaction among cancer patients and their disclosure network. This ICT innovation could also be incorporated in the existing telehealth system in Malaysia.

Using the rapid software prototyping approach, the main research activity is to create an artifact based on a rough approximation. The artifact will be tested and refined according to user feedback. For my research problem, I will develop the first version of the web portal using the effective web design guide. In each stage or version, I will carefully observe and document users' perception on multiple outcome variables like sense of privacy, usefulness and ease of use of the web portal. One possible way to capture users' perceptions is by using a "think aloud" technique. We can also use a technique called "aggregation" to quantify the system outcome. After each data collection, I will incorporate the users' suggestions and make necessary changes in next version of the program. I will then repeat the data collection process with end users until I find their suggestions reach saturation. I will need to observe all the outcome variables over time. The proposed duration of this prototyping process is between six to nine months. The key of this methodology is the iterative refinement process based on users' needs when they want to disclose sensitive health information over the web portal.

Expected outcomes

This research will be conducted over the duration of 24 months beginning of January 2007. It is fully funded by the Malaysia Cancer Council (MAKNA) as part of its annual cancer research award. The expected outcomes are the following:

1. a list of requirements addressing the disclosure and privacy concerns on cancer-specific web portal.
2. a web portal prototyping processes with user feedback.
3. a well developed web portal prototype.

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Address for correpondence

Nasriah Zakaria
Room 3.19
School of Electrical and Electronics Engineering
Engineering Campus, Universiti Sains Malaysia
Nibong Tebal, 14300 Penang MALAYSIA
Email: Nasriah.zakaria@gmail.com
Phone: 604-5996056