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## Information Systems and Healthcare XXVIII: The Information Needs of Family Carers in Collaborative Healthcare

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# Communications of the Association for Information Systems

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## Information Systems and Healthcare XXVIII: The Information Needs of Family Carers in Collaborative Healthcare

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### Abstract:

While the important role of family carers has been increasingly recognized in healthcare service provision, particularly for patients with acute or chronic illnesses, the family carer's information needs have not been well understood or adequately supported by health information systems. In this study, we explore the information needs of a family carer by analyzing the extensive online diary of a Vietnamese family carer supporting his wife, who was a lung cancer patient. The study provides a deep understanding of the information needs of the family carer and suggests a four-stage information journey model including identification, searching, interpretation and information sharing, and collaboration. A number of themes emerge from the study including the key role of the carer, information filtering by the carer, information sharing and collaboration, and the influence of Vietnamese culture. The paper concludes with a discussion of the requirements for health information systems that meet the needs of family carers.

**Keywords:** health information systems, information needs, culture, family carer, cancer

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## I. INTRODUCTION AND BACKGROUND

Health information systems support the planning, delivery, management, and evaluation of healthcare services through the use of information and communication technologies. These systems aim to support and coordinate the needs of various stakeholders. The stakeholders may include hospital administrators, doctors, nurses, allied health providers (e.g. physiotherapists, dietitians, social workers), families, carers, and, of course, the patients. Health information systems include hospital administration systems, electronic health records, computer aided diagnosis systems, healthcare decision support systems, imaging informatics, pharmaceutical systems, and patient health education systems [see for example Hovenga et al. 1996; Ayres et al. 2006; Bental et al. 2000].

Information about patients is typically distributed throughout these systems and needs to be integrated to obtain a “whole of patient view” that includes all available information about the patient and related medical information. Information dissemination and sharing amongst all involved stakeholders is important in achieving successful healthcare outcomes. However, the current level of information integration and dissemination in health information systems is low [Soar 2004]. Furthermore, although the use of information and communication technologies is transforming health service delivery, communication and interaction between different stakeholder groups remains a challenge [Schneider and Wagner 1993].

The traditional focus of health information systems has been on the provision of timely, accurate, and comprehensive information and medical knowledge to doctors, nurses, administration staff, hospital management, and other healthcare organizations [Civan and Pratt 2007; Thrasher et al. 2006]. More recently, the availability and growth of Internet-based medical information has led to the provision of information services to patients, their families and carers [Gerber and Eiser 2001; Altinkemer et al. 2006; Wilson 2003]. The availability of medical information and health information education is making patients and carers more informed about their medical situation [Bental et al. 2000; Eysenbach and Jadad 2001; Eysenbach 2003].

Patient-centered care is becoming increasingly important in order to provide continuous home-based care for patients and reduce hospital admissions and the length of hospital visits [Soar and Croll 2007; Wagner et al. 2005]. The information needs of patients and their family carers are crucial for effective care planning and delivery and treatment outcome evaluation. However, these needs have not been well understood or adequately supported by current health information systems.

## II. INFORMATION NEEDS OF PATIENTS AND FAMILY CARERS

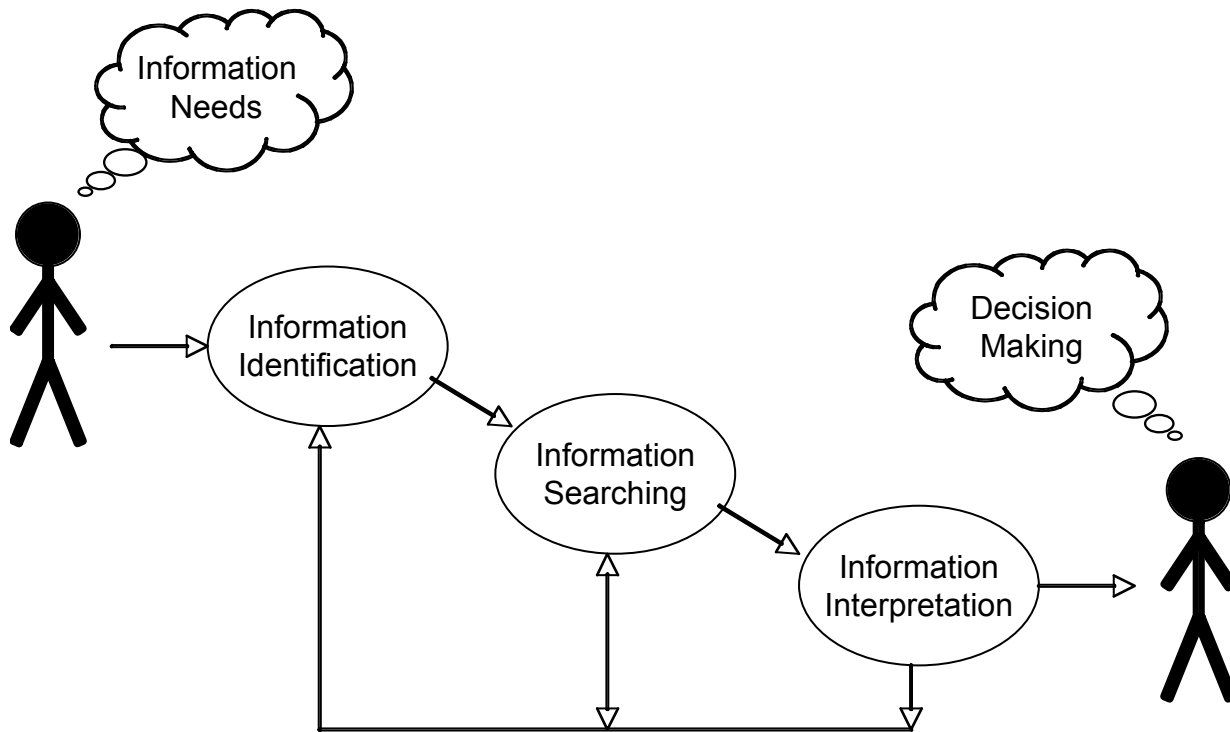
The information needs of patients and family carers, in particular their access to patient-specific information and illness-specific information, has recently emerged as an important area of research [Hersey et al. 1997; Wilson 1999; Eysenbach and Jadad 2001; Bamidis and Eaglestoneb 2006].

In their empirical study of a patient call centre, Adams and Blandford [2005] examined patient enquiries and the dynamics of their information needs in relation to evidence-based care. They concluded that both health practitioners and patients perceive current health information systems as inappropriate to their information needs, and argued for better integration of information systems with user communities and their practices. They proposed the *information journey model* [Adams et al. 2005; Adams and Blandford 2005] to describe the dynamic and changing information needs of patients. Two implications emerge from the Adams and Blandford [2005] study. First, the patient’s family was identified as playing an important role in all three stages of the patient’s information journey. This motivated us to explore the information needs of family carers. Second, the information journey model should be useful in exploring the information needs of family carers and consequently we have adopted it in our study. The information journey model is a process model comprising three stages and we have adapted it for this study as shown in Figure 1.

**Information Identification:** The family carer identifies information needs from their direct requirements (for example to prepare for a treatment consultation session with the doctor) or passive encounters from the media (for example an article about the recent spread of a disease in the town). Adams and Blandford [2005] highlighted the problem of poor awareness of what is available in public digital libraries in this stage.

**Information Searching:** The family carer searches for and gathers information based on their perceived information needs. Information resources, search time, and representation format play important roles during this stage. The family carer may iterate back to the information initiation stage to further clarify their information needs or move on to the information interpretation stage.

**Information Interpretation:** The family carer interprets the information for use in their decision-making. This is of great importance to family carers, clinicians, and patients and two issues emerge. First, how can valid interpretation of the information be supported? Second, how is the interpretation relevant to the family carer's specific needs? The family carer may iterate back to the information identification or searching stages to clarify their information needs and gather further information if necessary.



**Figure 1. Information Journey Model**

While the information journey model provides a useful framework for this paper, it does have some limitations. All three stages of the model occur within a social context and therefore information identification, searching, and interpretation are negotiated with others, particularly other family members. Furthermore, "information identification" seems to assume that information identification is unproblematic; that information is in fact identifiable, and can be dealt with by increased awareness. However, the case study interpretation does include substantial contextual analysis and discussion to clarify these limitations.

Family carers play an important role in providing integrated, continuous and home-based care for patients. Family carers have important knowledge and information needs and interact frequently with patients and clinicians [Docherty et al. 2008]. While current health information systems tend to focus on information needs and information dissemination between hospital management and administrators, clinicians including doctors and nurses, and patients [Soar 2004; Oliver and Robert 2006; Hovenga et al. 1996], little is understood about the information needs of family carers.

In order to effectively provide effective healthcare for the patient, the family carer needs access to medical knowledge and the patient's health information. It is sometimes assumed that family carers can obtain sufficient health information from public digital libraries, the media, and hospital information leaflets. See for example, Web sites addressing carers' needs such as EQUIP (2008), Northern Sydney Health Information for Carers (2008), Carers Australia (2007) and Mental Health (2007).

While such Web sites and information leaflets provide information about rights, responsibilities and care instructions in a systematic way, they address an anonymous carer and therefore do not address the specific concerns of the carer, such as “what is really happening to my loved one?” and “how can I best help them?” It is also assumed that family carers can obtain sufficient information about the patients’ health when they accompany them to a clinic (especially in the case of children, aged patients, patients with mental illnesses or other disabilities, or patients with a non-English speaking background). In practice, family carers often play a key role in the identification, selection, and interpretation of medical information.

To better understand the information needs (and information seeking behaviors) of the family carer, it is important to understand the triadic relationship between the patient, the family carer, and the clinician, and the complexity and dynamics of the social and medical context at the point of care [Nguyen and Shanks 2007]. The family carer’s information needs are influenced by the nature of the patient’s illness (diagnosis and prognosis), the availability of health information and the carer’s perception of his/her roles and responsibilities in relation to the patient. People’s perceptions of their roles and responsibilities in relation to others and their behaviors are influenced and informed by their national culture [Hofstede 2001]. Indeed, ethnicity and national culture were identified as important factors in care provision to terminally ill patients [Docherty et al. 2008; Spruyt 1999; Koffman and Higgison 2001]. In particular, there is limited understanding of the information needs of carers from ethnic communities [Docherty et al. 2008]. In Australia with a diversity of ethnic cultures, many home-based family carers and patients are from a non-English speaking background. Family carers are often seen as interpreters in clinical consultation sessions. Their roles and responsibilities as interpreters and carers are often mixed and not clearly understood.

In this paper, we extend previous research [Nguyen and Shanks 2007; Nguyen et al. 2008; Adams and Blandford 2005]. By exploring the information needs of a family carer, we address two questions: (1) What are information needs of family carers? (2) How do cultural factors influence the information needs of family carers? We do this by analyzing the extensive online diary of a Vietnamese family carer supporting his wife, who was a lung cancer patient. In the following section we discuss the research method and data analysis approach used. We then present an analysis of the data in the blog in terms of the information journey model. A number of themes that emerge from the study are then discussed. The paper concludes with a discussion of the requirements for health information systems to meet the needs of family carers.

### III. RESEARCH APPROACH—AN INTERPRETIVE STUDY

This study uses a qualitative, interpretive analysis [Walsham 1995; Benbasat et al. 1987] of a blog created by a Vietnamese man, Tran (pseudonym), who was the primary carer for his wife Le (pseudonym). The interpretive approach allows the researchers to gain an in-depth understanding of the nature and complexity of the processes that took place over a five-month period of time. Interpretive studies have been widely used in Information Systems [see for example Walsham 1995; Myers 1997] as well as healthcare research [for example see Graham and Nevil 2007].

Le was diagnosed with lung cancer when she was 28 years old, immediately after giving birth to her second child early in 2005. Le was treated at a public hospital in Hanoi, later at a private clinic in Singapore, and then back to Hanoi at two other hospitals. As a consequence of chemotherapy, her immune system was too weak to help her fight against a chest infection. She died in August 2005 in Hanoi. The nature of this disease and the patient’s family circumstance (two young children including an infant) put the patient, her family and particularly her primary carer (husband) through an intensive and emotional decision-making journey.

The data used in this case study is secondary data. The source was an online diary published on a Web site, i.e. a blog. The diary, which started from 25 March 2005 and ended on 25 August 2005 and contained over 42,000 words, was written by Tran, a 34-year-old software engineer, during the five months of his wife’s intensive treatment. The diary was a live story—a series of events, which happened as he and his wife were going through their fight against her lung cancer. The diary was referred to by the husband as “a sad fairy tale” as it had a sad ending which was not known to the writer-carer, the patient, nor the Web reader at the time of writing. It was real and live, and revealing and insightful to the researchers. It also strengthened the urgency and importance of the findings from this study to practice and research.

From the early days of the diagnosis, Tran knew very little about cancer. In order to provide care for his wife, and most of all, to save her life, he gradually learned about this life-threatening illness. It was a long on-going learning process as the illness developed and as he and his wife went through different stages of care planning and treatment. At first, he believed in Vietnamese traditional medicine and learned about it. Later, he learned more and more about Western contemporary medical knowledge and technologies used in cancer treatment. As he learned a lot about medical advancements and technologies in cancer treatment, and went through a range of different emotions, from hopeless to hopeful, denying to accepting the truth, he felt a strong need to write down and share his



experience with others. The diary documents their experience, step-by-step, at times day-by-day, about how they went through the treatment course, their physical and emotional reactions to it, and their learning and decision-making. The diary is a rich source of personal experiences, observations and reflections. In the diary, Tran also made reflective (and comparative) notes about treatments and working cultures at different places. The diary and the story of the couple were featured on television, various Vietnamese Web sites and newspapers. The Web site, in which his diary was published, attracted approximately 4,000 Web messages left by visitors, and by late 2007, there were over three million page viewers. The messages and stories gave support and encouragement to Tran and his wife, and shared with them personal experiences in fighting with cancer. The Web site (and its associated forum) became a rich source of information and support for other Vietnamese cancer patients and their families in Vietnam and overseas. The diary, visitors' stories and messages, which Tran referred to in his diary, were selected and used as an additional source of data for this study. The blog text is written in Vietnamese. Some English medical terminology is used occasionally. Images (medical CT scans and his family photos) published on the Web site were also collected to assist the researchers in their analysis of the text. All textual and multimedia data from the Web site were downloaded and stored for analysis.

Qualitative data was analyzed using the meaning condensation technique [Kvale 1996]. The researchers used a cyclical process of summarizing long passages of text from the diary into brief statements with condensed meaning. These statements were then coded and classified into categories, which were further analyzed for emergent raw themes. The raw themes were analyzed through the lens of different information stages of the information journal model (See Figure 1) and were used to refine these stages. Newly emergent themes were used to refine and extend the information journey model.

#### IV. THE INFORMATION JOURNEY OF THE CARER

The supportive care role that Tran played involved a complex information journey over a five-month period. We report the findings of our study in terms of the information journey model described earlier.

##### Information Identification

After giving birth to their second child, Le (the wife) was moved from a maternity ward to a ward at a respiratory department where she was diagnosed with cancer. Tran "was totally shocked for half a day" but after that he "resumed my (his) calmness and started fighting (with her cancer)." He decided to learn about the illness and ways to help his wife.

As a husband-carer, Tran knew and understood the patient very well, and had a clear and specific goal—to ensure her well-being and save her life. He struggled to accept the "shocking diagnosis" of lung cancer (which rarely happens to patients of her age) and learned about this life-threatening illness. As the illness developed and various treatment options were offered to her at different stages, his specific information needs changed over time. Specific direct "triggers" for information identification included the diagnosis; what he learned from talking to doctors, friends, families about different treatment options at different hospitals; and different cues from his direct observations of his wife's reactions to treatments, images and medical reports, or medicines given to her. Periodically, when seeing or hearing new terminology or names of medicines prescribed for his wife, he identified a new information need.

I had to give the pain relief Fentanyl (in the form of DUROGESIC transdermal patches) to my wife ... After reading carefully about this pain killer, I decided to give it to her.... Next morning, she said that she felt drowsy ... I don't know whether it was because of the new pain relief... at lunch time, ... I found an Internet Café, ... after careful reading about it I found out that Fentanyl could slow her heart rate ... and possible affect her respiration...I rushed back home to give her respiration support...and found out that she had started using an oxygen mask... [Later he removed the pain relief patch.] ... when I started to give treatments to my wife I was very anxious. I wanted a speedy recovery.... now I am more patient...

Initially, Tran knew very little about cancer and did not believe that modern treatment options could help. Therefore his information needs centered on which Vietnamese (Oriental) traditional medicines could cure cancer. For over one month, he learned a lot about Vietnamese traditional herbs, bought different herbs from Vietnam, USA, and Cuba, learned to mix and cook them, and gave them to his wife. As these attempts did not help, Tran and his father-in-law felt that they might need to look for an alternative treatment method. After an X ray scanning, he and his wife were shocked to see on the image that, "One lung was gone. Despite three or four different types of herbal mixes... how hopeless..."

His information needs changed. He was now looking for an explanation for the missing lung and for information about western treatment options. He consulted with a family relative (his aunt), who was also a doctor from another hospital in Hanoi, to seek information to explain why one lung was gone on the X ray image. After hearing a logical

explanation from her, his hope built up again. He decided to take his wife to Singapore for treatment. His information needs extended: he needed information about a particular doctor in Singapore, his approach to cancer treatment and his previous patients. He searched for information on the Internet about Doctor Jim (pseudonym) and his clinic. He also contacted the doctor's patients in Vietnam. His diary and numerous messages on his Web site show this common information need by cancer patients and their families: the need to find out about different clinicians' approaches and their reputations.

In Singapore, as his wife went through different scanning, testing, and treatment stages, Tran's information needs changed and extended over time. For example, before chemotherapy, his information needs concerned which foods might boost his wife's energy. After reading the names of the drugs given to his wife during the first chemotherapy session, he needed information about them and how they could help cure his wife's illness. He also wanted to know about the experiences of other cancer patients with chemotherapy. He used the Internet to search for information and also met and talked with many other cancer patients. His Web site (which published his diary) attracted many visitors including cancer patients and their families. They left messages and stories of support and encouragement, and suggestions and advice. Many times, over and over in his diary, he expressed his interest in reading stories from his Web visitors and the people he came to know in Singapore and Hanoi. Interestingly, he perceived that his wife's information needs to be different from his. He shared with his wife only the success stories he found, which is understandable but not recognized in many health information systems. His information needs changed as he became more involved in the course of treatment and took more ownership and control. Tran was astonished with the technologies used in cancer planning and treatment in Singapore and was always curious to learn more, for his wife and later for other cancer patients in Vietnam. He sought the opinions of many doctors (CT imaging practitioners, oncologists, dieticians, psychologists, etc.) about treatment plans. Later Tran and Le went back to Hanoi to continue the chemotherapy course. Again, Tran's information needs changed: how to best give his wife a combination of Western and traditional Vietnamese medicines. He traveled to villages to speak with traditional Vietnamese medical practitioners and find out about applications of their traditional methods. Events such as consultation and treatment sessions, his wife's reactions to them, and her illness stages, disrupted his learning process.

Over time, his information needs changed drastically from Vietnamese traditional medicines, to Western approaches. He also gathered information about Singaporean clinicians and their reputation, CT scanning technology, chemotherapy, radiotherapy, possible side effects and how to counteract them, diet planning for chemotherapy patients, and a psychological approach to pain relief and management (when his wife collapsed and had illusions) and how to give her injections at home. Two observations emerge. First, Tran's ability to identify his information needs was derived from various sources but largely based on clinical knowledge. Previous research identified two sources of information needs within the information identification stage: direct triggers and passive encounters [Adams and Blandford 2005] (see Section II for details). These two types of information needs respectively match two levels of medical informatics in Hersh's classification (1) clinical information and (2) public health information [Hersh 2002]. Clinical information refers to the information used by clinicians and patients in the care. Hersh [2002] further distinguishes two types of clinical information: patient-specific and knowledge-based. Patient-specific information refers to information generated and used in the care of an individual patient whereas knowledge-based information refers to scientific knowledge in medicine (knowledge about the illness and care concerning many patients). Public health information refers to information used in the population health control and prevention. Tran's information needs crossed the boundary between patient-specific and knowledge-based clinical information. He had rich patient-specific contextual information (for example, feelings and emotions, finance, values) and kept numerous medical reports about his wife from different hospitals and specialists. Even then, he did not have a complete set of medical notes and records as some were internal to the hospitals and specialists. Furthermore, although he gained some limited medical knowledge about the illness as a layman, he did not have (medical) knowledge-based information as a specialist.

Second, Tran's learning process was rather ad hoc, emergent, and fragmented. Lacking medical knowledge-based information, Tran did not know in advance what information he needed to search for. He used different emerging cues to find out what he needed to learn one step at a time. His emergent and ad-hoc identification of information needs highlights an information gap in healthcare between the contextual information (which can be provided by the patient and family) and the medical knowledge (possessed by the healthcare professional). On the one hand, Tran had rich contextual information, but lacked medical knowledge, therefore he could not put together different pieces of information to form a clear picture and identify missing pieces (information needs) in a structured, scientific way. On the other hand, the healthcare professionals, while possessing medical knowledge, did not have the "full," rich contextual picture of the patient and her family situation. While contextual information (events that happen outside the hospital, family emotions and values, and the patient's financial and social needs) is important for effective care provision, better medical knowledge would support the family carer's information identification process.

Therefore, a collaborative approach for medical specialists, patients and their carers is required to address this information gap and support the family carer's learning process and address their information needs.

### Information Searching

Tran used a variety of information resources to search for information he felt he needed. Public information resources about cancer and treatments were very limited in Vietnam. He used the Internet when he searched for information about different (Western) medicines and cancer treatment options and their side effects, and for information about traditional medicines. He commented: "... there are so many international Web sites about cancer... The Web site of the hospital (where his wife was diagnosed with cancer) was out of date and had limited information... (another Web site) specializes in cancer but it was provided by the Vietnamese-American cancer foundation. They provide good but still insufficient information. There are many Web sites in English... However, not everyone can read in English, information in Vietnamese is inadequate..." Tran also read brochures and information leaflets. As they were rather general and limited, he often sought specific information from his wife's doctors and nurses, his aunt doctor and friends who were doctors. There were times when Tran needed specific information to clarify diagnosis and a treatment plan but doctors were not always available: "Having received the report, I opened (the report) to read it. God, it was full of medical terminologies which are difficult to understand. It looks positive. I saw the phrase "largely resolved" ... and was happy about it. But I didn't understand what was resolved. ... I was very anxious and took two CT scans to the doctor 's office. He was in the middle of a consultation with another patient, and seemed to be in a rush. I told his assistant that I needed only five minutes." His information-gathering process was characterized with ad hoc events at which his information needs extended and changed from one topic to another. As the situation developed, Tran met with different health practitioners including pathologists, X-ray, and CT scanning staff, radiation oncologists, chemo-oncologists, a dietician, a psychologist, pharmacists, nurses at different hospitals, and Vietnamese traditional medical practitioners. Every time he met with them, he received their consultation, gathered some (specific) information and went to the Internet to search for more information to learn more (for example, about how a treatment would work), to read about possible side effects, to address his worries and fears, how other patients did this before, or to reflect upon his understanding and share with others his learning. Tran formed many friendships during the course of Le's treatments. He shared with them his experiences and learned a lot from their experiences as well. He also asked his aunt, a doctor, to examine his wife and learned about CT (computer tomography) scanning technology. Both of them were very curious, surprised about and interested in learning about this technology. Tran's network of friends became his informal resource of shared experiences and collective wisdom. Two observations emerge. First, the changes in and diversity of Tran's information needs show an ongoing and evidence-based learning process over five months rather than a structured instructor-led learning process often found in formal medical training. Sometimes, a new event, new observation or new information led him to search for further information. His knowledge base built up over time and also facilitated his further searches for information. Tran's information searching capabilities were therefore somewhat ad hoc and improved as his knowledge increased.

Second, Tran used different information resources and his communication skills to gather information. He used the Internet and general information leaflets to gather general information about cancer and treatment methods, about different pain relief drugs, etc. He consulted with doctors and nurses to find out patient-specific information (his wife's scan results, his wife's treatment plans etc). His excellent communication skills and his sincerity and eagerness to learn in order to save his wife helped him gained sympathy from various medical practitioners. He built very good relationships with many of them. He also built a network of support on the Internet – his Web site and Web discussion forum. He found valuable information and stories from his virtual friends as well as face-to-face friends.

### Information Interpretation

During his learning process about cancer and his continuous care provision, Tran interpreted and made sense of the information by relating it to observations of his wife's condition. For example, when he received CT scans of his wife's lungs in Singapore, he placed them next to previous X ray images against the glass window in his room in order understand the images. He put them in chronological sequence and tried to interpret what he saw by checking for changes. He interpreted the changes by relating them to his wife's symptoms over time, her treatment events and his observations when providing care for her. He felt empowered, satisfied and in control of the situation when he could make sense of what was happening. He also wanted to share his satisfaction with other readers on the Internet. Through times like this, he built up hope. At other times, he felt less hopeful. An example was when Tran's wife coughed out blood. He noted: "... it was a little pink, but it was enough to frighten us. During this stressful period, every accident like this becomes a concern, even a fear." A little while after this, he associated the coughing with a side effect of GemCisplat, a combination of chemotherapy drugs given to his wife. Although he read about GemCisplat on the Internet after the first chemotherapy session, it took him some time to relate his understanding of GemCisplat to his wife's cough. He was anxious to see the doctor to confirm his interpretation (of the information)





and the association between information and the event. From time to time, his experiences demonstrated a strong need to confirm his interpretation of information he found on the Internet with doctors. There was a time that he was worried that he would offend the doctors with his reading and learning. Later, he became more confident and discussed treatment options with the doctors. He learned about different medicines and even gave Neupogen injections to his wife at home. He made decisions about when to take his wife to hospital and when he could help her at home. Having become more confident in his ability to interpret information, Tran applied his knowledge to different cases he read from letters and stories on his Web site. There were a few occasions when he read stories from other patients and he explained the situation based on his accumulated knowledge about cancer and cancer stages. He often consulted with his father-in-law. They shared information and consulted with each other in decision making about how and where to give treatment to his wife. Four observations emerge, First, the husband carer had a strong need to confirm his interpretation of information. This was due to his ad hoc evidence-based learning process about his wife's illness and the treatment methods. This observation is consistent with our observations about the two previous stages of his information journey. Second, the husband carer's continuous sense-making of information and observations led to him accumulating knowledge about the patient's illness. As a result, he became more confident and was getting more involved in decision making. He became more confident when discussing treatment plans with the doctors and when providing care at home. Third, the husband carer's interpretation of information is closely associated with emotions: fearful, concerned, anxious, worried, hopeful, in control, empowered etc. He found strength, determination, and hope and believed that "where there is still life, there is still hope." The word *hope* was repeated many times in his diary. This did not change the ending of the story. However it was very important to him when providing care for his wife in the final stage of her lung cancer. Fourth, after information interpretation, Tran had a strong need to share his experience and learning with others and to learn from others. This was repeated many times. He needed to know what other carers did, their experiences and information about doctors, medicines, treatments, and side effects.

## V. DISCUSSION

The information needs of patients and their family carers are crucial for the effective planning and delivery of healthcare. We have explored the information needs of a family carer supporting his wife, who was a lung cancer patient. A number of themes emerged from the study.

### The Key Role of the Carer

It is clear that the Tran played a key role in supporting his wife by undertaking his information journey. As he was not directly suffering from the illness and was emotionally more stable, he could search, interpret and share information from different sources knowing that different possible future scenarios could happen. He remained hopeful and tried all possible sources for relevant information. His wife, Le, was tired from her illness and treatment for much of the time and did not have the energy, concentration or time to search for information. She may have been hesitant or felt guilty if she thought her illness was becoming a burden to others.

### Information Filtering

Who needs to know the truth? As his wife did not speak English well enough to understand doctors in Singapore, Tran played the role of an interpreter at the clinic. Surprisingly he "interpreted" for her not only in Singapore, but also in Hanoi. A diagnosis of cancer always has a shocking effect on any patient and their family. In this story, the husband wanted to protect his wife from the shock. So he "filtered" information to support her emotionally as well as encourage her to go through treatments. He shared this insight with readers on one of his Web pages:

"... just give 90% of truth ... don't say malignant ... just say a benign tumor."

As Le was an educated person, Tran still had to give her logical explanations to obtain her cooperation with the doctors. Before each visit to hospital, Tran shared hope while hiding fear with his wife. Later in Singapore, his father-in-law convinced him to tell her the whole truth because her health had deteriorated. Finally, they had to tell her. The family carers in this story believed they knew when the patient needed to know the whole truth about her illness.

There are varying views on patients' and their families' information access especially with regard to terminal illnesses (Clayton et al. 2005). In Western cultures, the carer's access to the patient's health records is often restricted although he/she may prefer to have full access. In this Vietnamese case, the family carer filters information while caring for the patient. We argue following in the section "Cultural Influences on the Carer's Information Needs" that this is best understood through the lens of Vietnamese national culture and its Confucian values.

## Information Sharing

Tran felt a strong need to share his experience and learning with others and to learn from them. He needed to know what other carers did, their experiences and information about doctors, medicines, treatments, and side effects. Although he noted that he had never written a diary previously in his life, Tran commented:

“... I feel a strong motivation to write down our experiences, in the hope of bringing something to you, a reader of my diary.”

Through his Web site, Tran met many new friends and was able to provide useful information:

“... we were able to assist some people, at least with information ...”

Tran shared his information and experiences and received great support from his family, colleagues and friends, healthcare practitioners and the wider community of Web users. This information sharing not only helped others but as a social networking activity provided Tran coping with emotions and stress.

Tran and his wife received tremendous emotional support from their extended family who were always available to help. Grandparents took care of grandchildren for the husband to care for his wife and travel with her to Singapore. Tran often consulted his aunt, who was a medical doctor, to receive explanations of medical terms and his wife's medical records. It is very important to note that while the doctors suggested and carried out the treatment (actions) based on their professional knowledge and training decision making skills, Tran and his family consulted, 'negotiated' with the doctors and made many decisions, for example:

“...the whole family 'voted' that my wife should stop after the fifth cycle of chemotherapy. I also considered opinions by doctors including those in Vietnam as well as in Singapore.”

His friends also provided emotional support and expertise and experience. He searched for explanations and aggressively collected information about contemporary cancer treatment approaches through personal contacts with medical practitioners, a family relative and a friend respectively.

Tran also contacted previous patients who received chemotherapy from the doctor recommended to him by his friend. His close contact and frequent conversations with various family friends, work friends and Web friends about medicines, treatment options, effects and side effects, and the nature of the illness are repeated many times throughout his diary. Tran's feelings about being able to explain and interpret information and his eagerness to share information after each event indicates that he felt empowered and in control—a source of energy that helped him in proving ongoing care and coping with his own tiredness and distress.

The strong influence of information sharing revealed in this study suggests enhancing and refining the information journey model [Adams and Blandford 2005] with an additional stage: information sharing, as indicated in Figure 2 following. Often, a family carer needs to share information and his/her interpretation of the information with the patient and the involved doctor(s) in decision-making rather than independently make a decision. Information sharing has also been identified as a key issue in other studies of the information needs of carers [Docherty et al. 2008].

## Cultural Influences on the Carer's Information Needs

Two important Vietnamese cultural influences observed in this study are the strong connection to Confucian values and a belief in traditional Vietnamese medicine. According to Vietnamese-Confucianism, three virtue-relationships for men include King and Subjects, Father and Son, and Husband and Wife and three virtue-relationships for women include Following Father, Following Husband, and Following Son. Although there have been significant changes in the Vietnamese society and the Confucian values and virtues have been questioned and challenged, some of them still exist and work in the background rather than the forefront as they did in the past. Tran's wife had an absolute trust on him and was comfortable with his decision-making. She followed all his instructions and suggestions about how and where to administer her treatments, demonstrating a strong connection to Confucian virtues in Vietnamese culture. Tran provided her with his strong protection, selfless devotion, endless love, and care. He protected his wife from the total truth about the illness, revealing only part of it: “carcinoma instead of cancer” and “tumors or benign tumors instead of malignant or metastasis.” He was worried that she would check the dictionary but she did not, she absolutely trusted that he would do his best for her. The carer's role and decision-making responsibility of the husband were well accepted in Vietnamese and Singaporean hospitals. There was a 'hidden' shared understanding between the husband, father-in-law and other doctors, nurses, and medical practitioners about the husband's role and responsibilities.



The second cultural factor observed in the diary was Tran's belief in traditional Vietnamese cancer treatment methods as complementary to "proper" (or Western) cancer treatments. He learned about traditional methods and medicines, and how to mix and apply them. He also sought an Oriental explanation of what cancer was and what caused it. He followed traditional Vietnamese wisdom "Có bệnh vái bốn phương" i.e., "When you're sick you need to look for all directions." Tran searched for different information about cancer treatments and applied a combination of both contemporary cancer treatment and Vietnamese traditional methods. Using both contemporary and traditional cancer treatment methods has become a popular approach that Vietnamese cancer patients and their families have adopted.

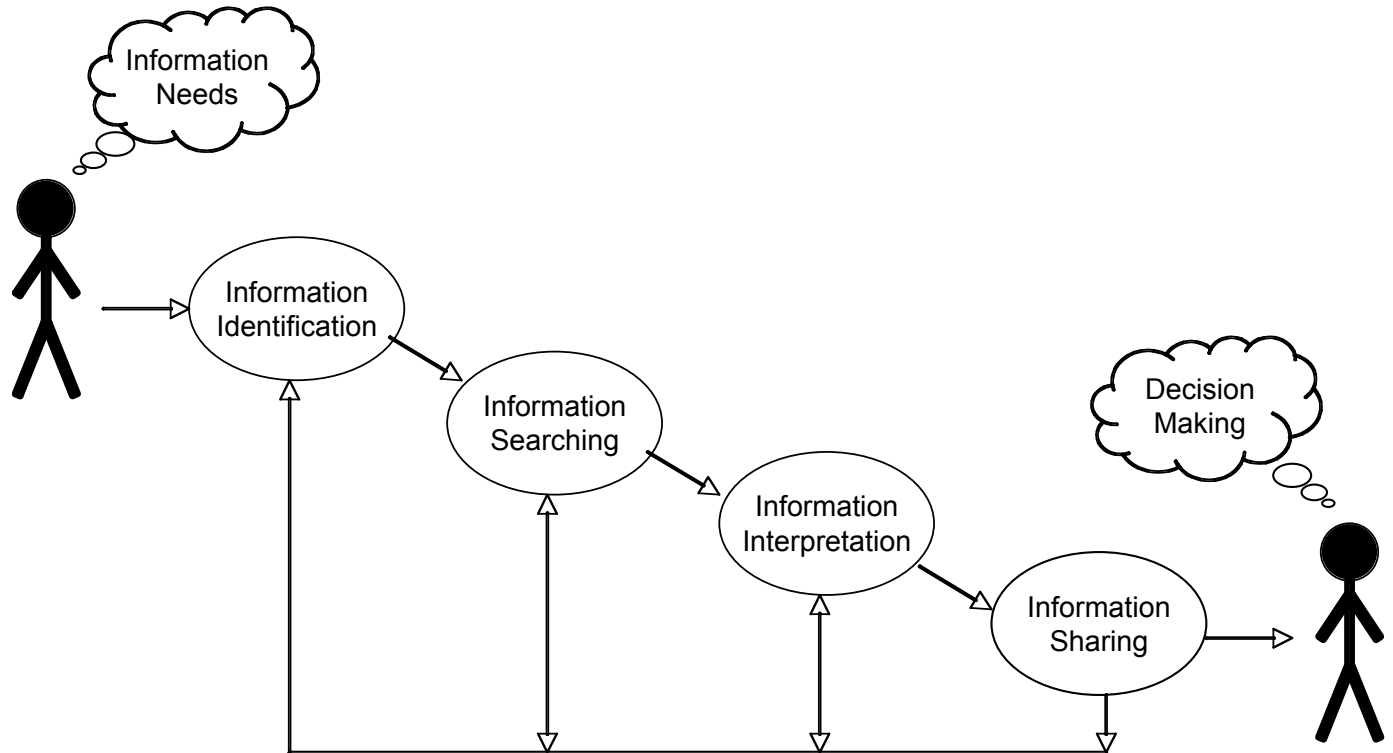


Figure 2. Revised Information Journey Model

## VI. CONCLUSION

Patient-centered and family care for patients with acute or chronic illness has been increasingly recognized in healthcare service provision [Wagner et al. 2005]. We have extended our previous work [Nguyen and Shanks 2007; Nguyen et al. 2008] and argued that the information needs of the family carer are best understood as an iterative process of information identification, information searching, information interpretation, and information sharing. We have refined and enhanced the information journey model [Adams and Blandford 2005].

The carer's lack of medical knowledge and his rich contextual knowledge about his wife's situation led to an information search process that was fragmented, improvised, and situated. Tran spent enormous time integrating and interpreting the information he received, using simple concepts and metaphorical thinking to understand the medical terms and treatment options. He shared the information and his understanding with other patients, carers and doctors to help cope with emotions and stress.

Tran's needs were not confined to information however. Social needs are best understood as relating to various forms of support (both given and received), including emotional, financial, wishing to learn from the experience of others, and the availability of social others during the ongoing process. Social network technologies hold great promise in responding to such needs, creating online communities that include the patient's immediate and extended family, friendship networks, other patients and their families, the wider community of "Web friends" and the professional care giver community at large. However, social network sites are generally limited in the support they provide for information rich tasks.

We also highlighted the cultural influences that infuse both information and social acts. We show a relationship between the family care decisions and cultural background. In Vietnamese families, the strong family relationships,

informed and influenced by Confucianism and traditional belief systems, still play a very important role. As this study is based on a Vietnamese case, further empirical research is required to examine the socio-cultural factors in a range of contexts.

Four implications for health information systems that meet the needs of family carers emerge from this study. First, the family carer is a key stakeholder in the provision of patient-centered healthcare. For successful care information resources including case-based digital libraries, public digital libraries, and effective communication mechanisms between medical teams, hospitals, and community support groups is required. The family carer should be included in care planning and delivery and decision-making.

Second, there should be assistance for family carers in finding and interpreting medical information that they have identified as important. Adequate access to and accurate interpretation of healthcare information by carers is important for the patient's and carer's emotion well being and decision-making.

Third, more support is required to enable information sharing within communities of patients and their family carers. This needs to be done with careful consideration to ensure that valid information is shared and distributed between the community of patients and families and to ensure legal and ethical requirements.

Fourth, the bridge between understanding information needs and designing supportive information systems is complex, but this is especially so in design contexts that involve multiple communities with different values, practices and needs for technology that are engaged in the collective effort of care provision. The design and implementation of such systems that blend elements of information technologies (databases, powerful and flexible search algorithms) with social technologies (social network sites, blogs) to best support practice that is both informationally rich and socially embedded is an important issue for further research.

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EDITOR'S NOTE: The following reference list contains the address of World Wide Web pages. Readers, who have the ability to access the Web directly from their computer or are reading the paper on the Web, can gain direct access to these references. Readers are warned, however, that:

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