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Lemai Nguyen

Deakin University, Lemai.nguyen@deakin.edu.au

Graeme Shanks

Melbourne University, gshanks@unimelb.edu.au

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Families as Carers - Information Needs in a Cultural Context

Lemai Nguyen
School of Information Systems
Deakin University
Vic, Australia
Email: lemai@deakin.edu.au

Graeme Shanks
Department of Information Systems
Melbourne University
Vic, Australia
Email: gshanks@unimelb.edu.au

Abstract

While the important role of family as a carer has been increasingly recognised in healthcare service provision, particularly for patients with acute or chronic illnesses, the carer's information needs have not been well understood and adequately supported by current health information systems. In order to effectively provide continuous and home-based care for the patient, a family relative as the primary carer needs sufficient access to medical knowledge and patient's health information. There are two challenges. First, being a family relative, the primary carer is often a non-medical practitioner. Second, in Australia, many primary carers are family relatives of patients from a non-English speaking background. They are often seen as interpreters in clinical consultation sessions. Their roles and responsibilities as an interpreter and a carer are often mixed and blurry. Therefore, their information needs are often seen as secondary to the patient or neglected. The primary carer's information needs are currently not yet well understood.

This paper reports finding from a case study which examines an on-line diary of a husband-carer who provided support and care for his wife, who at the time of care was a lung cancer patient. The case study examines an on-going learning process that the husband went through, identifies information needs by the carer and cultural factors which played an important role in the husband's interpretation of information, decision making and provision of care. The finding extends a current model of the user's information needs in the literature and suggests implications for further research into developing health information systems to meet information needs by the family carer.

Keywords

Health information systems, information needs, cultural, carer, cancer

Introduction and Background

Family as the Primary Carer - a Missing Link in the Current Health Information Systems

There exists a wide range of health information systems adopted by medical practitioners: hospital administration systems, electronic health records, computer aided diagnosis systems, healthcare decision support systems, laboratory systems, imaging informatics, electronic communication and supplied chain management systems, pharmaceutical systems, and patients' health education systems (see for example in Hovenga, Kidd & Cesnik 1996; Bental et al. 2000; Soar 2004). In addition to their specific objectives, all these health information systems share an objective of assisting medical practitioners in diagnosis, care planning and delivery, and evaluation of treatment outcome through patient information capture and dissemination, and medical knowledge provision. Still, according to Soar (2004), the current level of information integration and dissemination in healthcare is low: "there is a low level of quality and comprehensive information at the point of care". Schneider and Wagner (1993) argued for the importance of information sharing through face-to-face as well as computer-based collaboration between healthcare teams. Among a number of challenges to healthcare knowledge management systems, there is a challenge to facilitate the integration and dissemination of quality and comprehensive information including laboratory results, patient clinical records and pharmacy records between health care providers (Soar 2004; Oliver & Robert 2006).

Traditionally, the focus of the information integration and dissemination has been on the provision of timely, accurate and comprehensive information and medical knowledge to doctors, nurses, others clinicians,

administration staff, hospital management, and healthcare organisations. More recently, the availability and growth of the Internet-based medical information leads to a shift in studying and providing information services to the patient (Gerber & Eiser 2001). There is a need to close the knowledge gap between the clinician and the patient to increase health information education to general public as well as to individual patients (Bental et al. 2000; Eysenbach & Jadad 2001; Eysenbach 2003). Furthermore, the cooperation by the patient's family with the hospital in providing integrated, continuous home-based care for the patient has been increasingly acknowledged. Patients and their families provide the clinician with information about their symptoms and receive information about diagnosis, treatment options, and home-based care provision. Therefore, their information needs and access to medical information and knowledge is important in care planning and deliver and treatment outcome evaluation. However, information needs by families as (primary home-based) carers has not been explored nor adequately addressed in previous studies.

Information Needs by Patients and their Family Care Givers

Over the last decade, consumer's health informatics has emerged as an important research topic in health information management to study the patient's access to health information, their information needs and information seeking behaviours (Hersey, Matheson & Lohr 1997; Wilson 1999; Eysenbach & Jadad 2001; Bamidis & Eaglestone 2006). More recent research (Adams, Blandford & Attfield 2005; Adams & Blandford 2005) examines dynamics of information needs by patient in their applications health digital libraries in evidence-based care. The researchers analysed the patient's information requirements, facilitation and interpretation and concluded that both health practitioners and patients perceive current health information systems as inappropriate to their information needs. The authors also suggest an integration of technology within user communities and their practice to address the temporal elements and changing information needs be required. An 'information journey' model has been proposed (Adams & Blandford 2005) to describe the changing information needs by patients. According to the information journey model (Adams & Blandford 2005; Adams, Blandford & Attfield 2005), there are three stages: information initiation, facilitation and interpretation.

- At the Information Initiation stage, the patient identifies information needs from their direct needs (for example to prepare for a treatment consultation session with the doctor) or passive encounters from media (for example an article about a recent spread of a disease in the town). Adams and Blandford (2005) highlighted poor awareness by patients of what is available in public digital libraries.
- At the Information Facilitation stage, the patient searches for and gathers information based on the information needs identified from the Information Initiation. Information resources, search time, and representation format play an important role during this stage. This stage may lead the patient back to the identification of new information needs (Information Initiation) or lead to the patient to the Information Interpretation stage.
- The interpretation of information is of great importance to both the clinician and patient as it has impact on their decision making. Based on Adams and Blandford's study (2005), two issues with on-line reading from public digital libraries include (i) how to ensure a valid interpretation of information and (ii) how to obtain information analysis relevant to the patient's specific needs.

The above information journey model was developed through an examination of the information needs by users of digital libraries in two domains of health care and academia. There are two implications for our study. First, in their study with a Patient Call Centre, Adams and Blandford (2005) examined patient's enquiries and their information journey and identified the patient's family as playing a role in all the three stages of the patient's information initiation, facilitation and interpretation. This strengthens our argument to understand information needs by the patient's family as a care giver. Second, the model captures major activities in patient's information needs and thus can be useful in understanding the carer's information needs. In the study reported in this paper, the information journey model was adopted as a theoretical framework to analyse qualitative data. As a result, the study suggests extending the model to describe the carer's information needs more comprehensively.

Further, families play a role not only in the three stages of the patient's information journey (Adams & Blandford 2005), they are important in providing integrated and continuous care for the patient. While current health information systems tend to focus on information needs and information dissemination between the doctors, nurses, other medical practitioners, hospital administration, and the patient (Soar 2004; Oliver & Robert 2006; Hovenga, Kidd & Cesnik 1996), little is understood about information needs by a family relative as a carer. Being a family relative, the primary carer is often a non-medical practitioner. In order to effectively provide continuous and home-based care for the patient, the family relative as the primary carer needs sufficient access to medical knowledge and patient's health information. There is an assumption that family care givers can obtain sufficient health information from public digital libraries (the Internet), media and hospital information leaflets. Web sites addressing carers exist, for example EQUIP <http://www.equip.nhs.uk>; Northern

Sydney Central Coast Health (<http://www.cancercare.org.au/www/html/277-information-for-carers.asp>); Carers Australia (<http://www.carersaustralia.com.au/>), and Mental Health (<http://www.health.vic.gov.au/mentalhealth/carers.htm>). While such Web sites and information leaflets provide information about rights, responsibilities and care instructions in a structured way, they address an anonymous carer thus do not address specific concerns of the carer, such as what is really happening to my loved one and how best I can do to help him/her. There is another assumption that family care givers can sufficiently obtain the patient's health information when they accompany the patient to clinic (especially in cases of children, aged patients, patients with mental illnesses or other disabilities, or patients with a non-English speaking background). In practice, family care givers often play in the background of the consultation and treatment process, their idiosyncratic information needs and patterns of information seeking behaviours should be but have not been explored and understood. Therefore, integrated information about general health knowledge, care instructions and specific patient health conditions is not well provided.

To understand information needs (and information seeking behaviours) by the family carer, it is important to understand the relationship between the patient and the care giver, and the complexity and dynamics of the social and medical context at the point of care. This is because the care giver's information needs would be influenced by the relationship between the care giver, the patient and the clinician, and by the nature of the patient's illness (diagnosis and prognosis). The care giver's information seeking behaviours will be influenced by the availability of health information and healthcare information infrastructure, the patient's diagnosis and treatment course, and by the carer's perception of his/her roles and responsibilities. It has been widely acknowledged that people's perception about their roles and responsibilities in relation to others, and their behaviours are influenced and informed by their national culture (Hofstede 2001). In Australia with a diversity of ethnic cultures, many home-based carers are family relatives of patients from a non-English speaking background. They are often seen as interpreters in clinical consultation sessions. Their roles and responsibilities as an interpreter and a carer are often mixed and not clearly understood. Therefore, their information needs tend to be seen as secondary to the patient and not met in current health information systems.

Two questions emerge from the above discussion:

- What are information needs of the family carer?
- What are cultural factors which influence information needs by the family carer?

These two questions will be addressed in this paper. The next section will briefly describe the adopted research approach. This will be followed by two sections which present findings in terms of the above two questions. The conclusion section will summary findings and outline implications for practice and further research.

Research Approach – An Interpretive Case Study

The research approach adopted in this study is a qualitative interpretive case study (Benbasat, Goldstein & Mead 1987; Walsham 1995; Yin 2002). A qualitative interpretive case study enables the researcher to explore and induce new concepts from a phenomenon (such as an event or organisation) in its natural setting through examining qualitative data gathered from one or multiple entities (Benbasat, Goldstein & Mead 1987). In this study, a qualitative and interpretive approach enabled the researchers to gain an in-depth understanding of the information needs and on-going information journey by a research subject - a husband care giver - when he provided care to his beloved wife - a lung cancer patient. Phan Van Hoa was the primary carer for his wife Lan Anh. Lan Anh was diagnosed of lung cancer when she was 28 years old, immediately after giving birth to their second child early in 2005. Lan Anh was treated at a public hospital in Hanoi, later in a private clinic in Singapore, and 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 information journey and decision making process.

The data used in this case study is secondary data. The primary source was an on-line diary published on a Web site in a fashion similar to a blog. The diary, which started from 25/03/2005 and ended on 25/08/2005 and contained over 42 thousands words, was written by Phan Van Hoa during these 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 in their fight against her lung cancer. The diary was refereed to by the husband as 'a sad fairly tale' as it had a sad ending which was not known to the writer-carer, the patient, nor the Web reader. 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 into health information systems.

From early days of the diagnosis, Phan Van Hoa knew very little about cancer. In order to provide care for her, 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 course. At first, he believed in Vietnamese traditional medicine and learned about them. 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 shows their experience, step by step, at times day by day, 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, Phan Van Hoa 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 TV, various Vietnamese Web sites and newspapers. The Web site, where his diary was published, attracted about four thousands Web messages left by the Web site visitors, by now there are over three millions page views. The messages and stories gave support encouragement to and shared with Phan Van Hoa and his wife their personal experiences in their 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 and visitors' stories and messages which Phan Van Hoa referred to in his diary were selected and used as an additional source of data for this case study. The text is written in Vietnamese. Some English medical terminologies are used occasionally. Images (medical CT scans and his family photos) published on the Web sites were also collected to assist the researchers in their analysis of the text.

Meaning condensation technique was adopted to analyse collected qualitative data (Kvale 1996). The researchers undertook a cyclic process of summarising long texts from the diary to brief statements with condensed meaning, coding and classifying those statements into categories, and identifying themes and exploring theme relationships. This inductive process allowed new concepts (themes and their relationships) to emerge and be internally validated.

Information Journey by the Carer – an On-going and Evidence-based Learning Process

The patient's information journey model (Adams & Blandford 2005; Adams, Blandford & Attfield 2005) was adopted as a theoretical framework to analyse the information needs by Phan Van Hoa, the husband carer. Phan Van Hoa's information journey consists of many short cycles of the three stages of Information Initiation, Information Facilitation/Gathering and Information Interpretation.

Information Initiation

As a husband care giver, Phan Van Hoa has one specific patient, whom he knew and understood very well; therefore at the Information Initiation stage, he had active needs – to save her well being and her life. He struggled to accept the '*shocking diagnosis*' of lung cancer (which rarely happens to patients at 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 this carer's information initiation stage include the diagnosis, what he learns from talking to doctors, friends, families about different treatment options at different hospitals, and all different cues from his direct observations of his wife's reactions to treatments, images and medical reports, or medicines given to her. Every now and then, when seeing or hearing new terminologies or names of medicines prescribed to his wife, he identified a new information need: "*I had to give pain relief Fantany (in the form of DUROGESIC transdermal patches) to my wife...After rereading 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, ... 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..." Based on medical diagnosis, scans and reports, and all cues he read from his wife's reactions to treatments, he identified further information needs. For example, after giving birth to their second child, Lan And (the wife) was moved from a maternity ward to a ward at a respiratory department where she was diagnosed with cancer. Phan Van Hoa "*was totally shocked for half a day*" after that he "*resumed my (his) calmness and started fighting (with her cancer)*". He decided to learn about this illness and ways to help her.

At that time, he knew very little about cancer and did not believe that modern treatment options could help. Therefore he perceived his information needs as which of 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, which he did, and gave them to his wife. As all these attempts did not help, Phan Van Hoa 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 FOUR DIFFERENT TYPES OF HERBAL MIXES... HOW HOPELESS...*”. His information needs changed: looking for an explanation of the missing lung and looking 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 film. After hearing a logical explanation from her, his hope built up again. He decided to take his wife to Singapore. His information needs extended: he needs information about Jim¹, a doctor in Singapore, and information about Doctor Jim's approach to cancer treatment and his previous patients. He searched for information on the Internet about Doctor Jim and his clinic. He also contacted Doctor Jim's patients in Vietnam. His diary and numerous messages on his Web site show this common information need by cancer patients and their families: to find out about different clinicians' approaches and their reputation (successful cases).

In Singapore, as his wife went through different scanning, testing and treatment stages, Phan Van Hoa information needs changed and extended over time. For example, before chemotherapy, he perceived his information needs as which would be good food menu to boost her energy. After reading the names of the chemo-drugs given to his wife during the first chemotherapy session, he needed information about them and how it could help cure his wife's illness. He also wanted to know about experiences that other cancer patients had with chemotherapy. Therefore he used the Internet to search for information. He also met and talked with many other cancer patients. His Web site (which published the diary) attracted many visitors, cancer patients and their families. They left messages and stories of support and encouragement, and suggestions and advices. Many times, over and over in his diary, he expressed his interest in reading stories from his Web visitors and people he came to know in Singapore and Hanoi. Interestingly, he perceived that his wife's information needs as different from his. He shared with his wife only success stories he found, which is understandable, but not recognised in many health information systems.

His information needs extended as he became more involved in the treatment course and took more ownership and control. Phan Van Hoa was very amazed with 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 asked and discussed with various doctors (CT imaging practitioners, oncologists, dieticians, psychologists, etc. about their opinions and treatment plans. Later they went back to Hanoi to continue the chemotherapy course. Again, Phan Van Hoa's information needs extended: how best to give his wife a combination of Western as well as Vietnamese medicines. He travelled to villages to find Vietnamese traditional medical practitioners to find information and explanation about cancer from a mix of Oriental and Western points of view, and their applications of traditional methods.

Events such as consultation and treatment sessions, his wife's reactions to them, and her illness stages, disrupted his learning process. At such events, information needs changed, and Phan Van Hoa moved to learn different medical topics. His information needs changed drastically from Vietnamese traditional medicines, to Western approaches, 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), how to give her injections at home, and so on.

Two interesting observations emerge:

- First, being a non-clinician carer he did not know in advance what information he would need to search for and what is available, his learning process was rather ad hoc and fragmented. He had to use different cues to find out what he needed to learn one step at a time. All these different cues and triggers while leading him to (build up) a fragmented knowledge base, they were puzzle pieces around one specific patient going through different doctors and nurses, homes and hospitals. Those puzzle pieces (from the carer's perspective) formed a coherent, patient-specific picture which healthcare practitioners and healthcare organisations could not see or access to - they did not have time to ask about all of them. Although the carer had rich contextual information, he was not informed about his (possible) information needs to enable an effective search.
- Second, the information initiation recognises two sources of information needs: direct needs and passive encounters. These two sources match a classification of health information (i) patient-specific (or case-based) and (ii) public (or structured). In practice, there is a form of collective or shared information when a community of patients and families shares their experiences and learning, their doctors' approaches and reputation. This is a type of information needed by many other patients and their families.

¹ A pseudoname to protect the doctor's identity.

Information Gathering and Facilitation

Phan Van Hoa 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 even when he searched for traditional medicines as well as when he searched for information and side effects of different (Western) medicines and cancer treatments options. He commented: *“there are so many international Web sites about cancer...The Website of the hospital K (where his wife was diagnosed with cancer) was out-of-date and had limited information... (Another Web site) is specialised 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”...*

Phan Van Hoa 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 Phan Van Hoa 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 Doctor Lee's² 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 5 minutes.”*

His information gathering process was characterised with ad-hoc events at which his information needs extended and changed from one topic to another. As the situation developed, Phan Van Hoa met with different health practitioners including Pathologists, X-ray and CT scanning staff, Radiation oncologists, Chemo-oncologists, a Dietician, a Psychologist, Pharmacists, and 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 (how it would work), to read about possible side effects, to address his worries (and fear) how other patients did this before, - or to reflect upon his understanding and share with other his learning.

Phan Van Hoa formed many friends during the course of treatments. He shared with them his experiences and learned a lot from their experiences as well. He also asked his aunt to examine his wife and learned about CT (computer tomography) scanning technology. Both of them were very curious, amazed about and interested in learning about this technology. Phan Van Hoa's network of friends became his different (off-line or on-line) informal resources of shared experiences and collective wisdom.

Two interesting observations emerge:

- Changes and diversity of Phan Van Hoa's information needs show an on-going and evidence-based learning process of 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 facilitated his further search for information.
- Phan Van Hoa used different information resources and 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 killer drugs, etc. He consulted with doctors and nurses to find out patient-specific information (his wife's scanning results, his wife's treatment plans etc). His excellent communication skills and his sincere and eagerness to learn in order to save his wife helped him gained sympathy from various medical practitioners. He has built very good relationships with many of them. He also built a network of support on the Internet – his Web site and Web forum. He found valuable information and stories from his virtual friends as well as face-to-face friends.

Information Interpretation

During his on-going learning process about cancer and his continuous care provision process, Phan Van Hoa always interpreted information he received, observed his wife, related information with observations, and made sense of what happened. 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 to apply his information and knowledge to examine the images. He put them in a chronological sequence and tried to interpret what he saw. He examined the images carefully, checked and looked for changes, interpreted changes and related them to his wife's symptoms over time, the treatment events and his observations when providing care for her. He felt power, satisfaction 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.

^{2 2} A pseudoname to protect the doctor's identity.

Another example: when his wife coughed out blood, Phan Van Hoa said "*it was 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 GemCisplatin a combination of chemotherapy drugs given to his wife. Although he read about GemCisplatin from the Internet after the first chemotherapy session, it took him some time to relate his understanding of GemCisplatin to his wife's cough. He was anxious to see the doctor to confirm his interpretation (of information) and association between information and the event). From time to time, his experiences show 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 doctor 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 when to take his wife to hospital and when he could help her at home.

Having become confident with his ability to interpret information, Phan Van Hoa applied his knowledge to different cases he read from letters and stories on his Web site. There are a few occasions when he heard 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 of how and where to give treatment to his wife.

Four observations emerge:

- 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 treatment methods. This observation is consistent with our observations about the two previous stages of his information journey.
- The husband carer's continuous sense-making of information and observations led to his accumulative knowledge about the patient's illness. As a result, he became more confident and was getting more involved into decision making. He became more confident when discussing treatment plans with the doctors and when providing care at home.
- The husband carer's interpretation of information is closely associated with emotions: fearful, concerned, anxious, worried, hopeful, in control, power etc. He found strength, determination and hope in Doctor Jim's motto: *Where is still life, there is full of hope*. The word *hope* was repeated times and times in his diary. This did not change the ending of the story; however it was so important to him when providing care for the patient at the final stage of lung cancer.
- After information interpretation, the husband had a strong need to share his experience and learning with others and to learn from others. This was also repeated times and times. The husband carer needed to know how other people did, their experiences and information about doctors, medicines, treatments, side effects.

Other Observations

We made some other interesting observations which indicated possible differences between the patient's and the carer's information needs:

- Information needs - Who needs to know the truth? As his wife did not speak English well enough to understand doctors in Singapore, Phan Van Hoa played a role of an interpreter at the clinic. What really surprised us was that he 'interpreted' for her in not only 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 with readers on one of his Web pages: *just give 90% of truth ... don't say malignant ... just say a benign tumour*. As his wife was an educated person, he still had to give her a logical explanation about everything to obtain her cooperation with the doctors. She was quite hopeful and had some good time taking sight seeing tours or small shopping trips with her husband in Singapore. Before every visit to hospital, the husband 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 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.
- Information search time: As the carer was not directly suffering from the illness, he was emotionally more stable and could read and search for information from different sources knowing that different possible scenarios could happen. In addition, the patient was tired from her illness and treatments most of the time. She physically could not have energy, concentration and time to search for information.

- Interpreting and filtering information: He learned from stories of survivors and victims of cancer but filtered information when sharing with her letters of support.
- The husband carer always tried to search for all possible ways and make use of information he found. A 'theme' appeared throughout the diary - his information journey: Trying all possible ways and Keeping hope. He hoped for miracle when there was no other ways left. A patient might be hesitant or feel guilty if they think their illness becomes a burden to others.

While above could be related to information needs by clinician care givers when providing care to inpatients, the husband care giver had only one patient and had a very close relationship with the patient. Therefore, their degrees of motivation and time/effort devotion for their information needs would be different.

Cultural Factors Influence the Carer's Information Needs

Phan Van Hoa'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 give her treatments. This shows a strong connection to Confucian virtues in Vietnamese culture. Although there have been a lot of significant changes in the Vietnamese society, as a result the Confucian values and virtues have been questioned and challenged. Still, some of the Confucian virtues still exist and play in the background rather than the forefront as in the old days. 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. Phan Van Hoa's wife was an educated woman. This did not stop her from looking up to him, consulting with him but trust information and decision making from him and her father. Phan Van Hoa provided her with his strong protection, selfless devotion, endless love and care. He hid the total truth about the illness and revealed only part of it: "*carcinoma instead of cancer*" and "*tumours or benign tumours instead of malignant or metastasis*". He was worried that she would check the dictionary but she did not, she absolutely trusted him that he would do his best for her. As shown in the diary, the care-giver'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.

Another cultural factor observed in the diary was the husband's belief in traditional Vietnamese cancer treatment methods as complementary to '*proper*' (or Western) cancer treatments. He learned about traditional methods and medicines, and learned to mix and apply them. Further he sought an Oriental explanation of what cancer was and what caused it. He followed an old Vietnamese wisdom "*Có bệnh vái bốn phương*" i.e. "when you're sick you need to look for all directions". This proverb means "when you are sick, you need to try every way (and every medicine)". Phan Van Hoa 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, informal and semi-formal approach that cancer patients and their families have adopted in Vietnam. In Australia, perhaps Vietnamese-Australian cancer patients and their families take a similar approach but rather informally and in an un-informed manner.

Summary and Conclusion

Families as carers play an important role in cooperating with healthcare practitioners in providing integrated and continuous care for patients. However, families as carers are still in the background in care planning and delivery. Current health information systems tend to focus on meeting information needs by healthcare practitioners and organisations, and patients, or general public. Carers' information needs are perhaps assumed to be addressed through health information Web sites, hospital leaflets and media to general public. There is a lack of an informed approach to meeting the family carer's specific information needs and taking into account their cultural factors.

This paper reports findings from an interpretive case study of a husband care giver providing care for his wife, a lung cancer patient. Using the information journey model (Adams & Blandford 2005), we analyse qualitative data from an on-line live diary by the husband. Our analysis confirms the three stages of the model and reveals a deep understanding of information needs by the husband care giver in the case study. In addressing his information needs, the family care giver went through an on-going, ad-hoc and evidence-based learning process consisting of many cycles of the three stages of the information needs model. Information needs changed and extended in an opportunistic way as the situation emerged – events which continually occurred at home and at hospitals, various diagnosis and medical reports arrived, consultations and treatments took place – and triggered new information needs and shaped his information journey. The dynamics of the family carer's information needs confirms and extends Attfield and his colleagues' observation that the patient's information needs before and after the clinical consultation vary (Attfield, Adams & Blandford 2006). Our study also suggests extending

and refining the previous information journey model (Adams & Blandford 2005) with additional stages: information evaluation (confirmation), information application (decision making), and information sharing (with the patient and others). Further, this study identified some cultural factors which influenced the information needs by the husband carer.

Findings from our study suggest three implications to health information systems practice. First, an integration of a case-based digital library, public digital libraries, an inclusive communication mechanism with the medical team, and hospital and community support groups is required to understand and address information needs by the family carer. Currently, only referral doctors and local doctors are included in the hospital healthcare team and care planning and delivery communication loop. Families as carers also need to be included in an informed way. Second, there should be support to assist family care-givers in their interpreting the information and to confirm/clarify/correct their interpretation. An adequate access to and an accurate interpretation of healthcare information by the carer is important in the patient and carer's emotion handling and decision making, and in turn care quality and outcome. This has not always been recognised in practice. Third, more support is required to enable information sharing within a community of patients and their family care-givers. 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.

Our future research tasks include:

- Conducting more case studies in Australia to further refine and extend the information journey model to describe complex and dynamic information needs by the family care-giver more comprehensively, particularly in cases of acute or chronic illnesses.
- By adopting a theoretical framework to understand cultural factors, extending our understanding of which and how cultural factors influence the family carer's information needs.
- Based on the outcome of the above tasks, building a theoretical framework and a health information system to support information needs for carers and patients.

References

- Adams, A. & Blandford, A. 2005, 'Digital libraries' support for the user's Information Journey', paper presented to IEEE and ACM Joint conference of digital libraries ACM/IEEE JCDL 2005.
- Adams, A., Blandford, A. & Attfield, S. 2005, 'Implementing digital resources for clinicians' and patients' varying needs', paper presented to BCS Healthcare Computing 2005.
- Attfield, S., Adams, A. & Blandford, A. 2006, 'Patient information needs: pre and post consultation.' *Health Informatics Journal*, vol. 12, pp. 165-77.
- Bamidis, P.D. & Eaglestone, B. 2006, 'Special Issue: Health Information management: a retrospective account of a decade of iSHMR events and highlights from iSHIMR2005', *Health Informatics Journal*, vol. 12, no. 1, pp. 5-12.
- Benbasat, I., Goldstein, D.K. & Mead, M. 1987, 'The Case Research Strategy in Studies of Information Systems.' *MIS Quarterly*, vol. 11, no. 3, pp. 368-86.
- Bental, D., Cawsey, A., Pearson, J. & Jones, R. 2000, 'Adapting Web-Based Information to the Needs of Patients with Cancer', paper presented to the proceedings of International Conference on Adaptive Hypermedia and Web-based systems, Trento, Italy, August.
- Eysenbach, G. 2003, 'Consumer health informatics', *BMJ*, vol. 320, no. 7251, pp. 1713-6.
- Eysenbach, G. & Jadad, A.R. 2001, 'Evidence-based Patient Choice and Consumer health informatics in the Internet age', *Journal of Medical Internet Research*, vol. 3, no. 2.
- Gerber, B.S. & Eiser, A.R. 2001, 'The Patient-Physician Relationship in the Internet Age: Future Prospects and the Research Agenda', *Journal of Medical Internet Research*, vol. 3, no. 2, p. e15.
- Hersey, J.C., Matheson, J. & Lohr, K.N. 1997, *Consumer Health Informatics and Patient Decision making*, Report NR AHCPR - Publication No.98-N001, Rockville.
- Hofstede, G. 2001, *Culture's Consequences: Comparing Values, Behaviors, Institutions, and Organizations Across Nations*, Sage, Thousand Oaks.
- Hovenga, E., Kidd, M. & Cesnik, B. 1996, *Health Informatics: An Overview*, Churchill Livingstone, Australia.

- Kvale, S. 1996, *Interviews: an introduction to qualitative research interviewing*, Sage Publications, Thousand Oaks, Calif.
- Oliver, K.B. & Robert, N.K. 2006, 'Working towards the informationist', *Health Informatics Journal*, vol. 12, no. 1, pp. 41-8.
- Schneider, K. & Wagner, I. 1993, 'Constructing the 'Dossier Représentatif': Computer-Based Information-sharing in French Hospitals', *Computer Supported Cooperative Work*, vol. 1, no. 4, pp. 229-53.
- Soar, J. 2004, 'Improving health and public safety through knowledge management', paper presented to Thailand International Conference on Knowledge Management, Bangkok, Thailand., 24-25 November.
- Walsham, G. 1995, 'Interpretive case studies in IS research: Nature and method', *European Journal of Information Systems*, no. 4, pp. 74-81.
- Wilson, S.M. 1999, 'Impact of the internet on primary care staff in Glasgow', *Journal of Medical Internet Research*, vol. 1, no. 2.
- Yin, R.K. 2002, *Case Study Research, Design and Methods*, 3rd edition edn, Sage Publications, Newbury Park.

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