

THE PATIENT-CAREGIVER INTEGRATED NETWORK

By

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## CHAPTER I

### INTRODUCTION

“Your test results show you have cancer!”

This is a powerful and life changing diagnosis. In order to effectively deal with a cancer diagnosis and cancer treatment, communication occurs among clinicians, patients, families, friends and others affected by the illness. This communication is an important part of the entire treatment process.

The following composite scenario paints a picture of some of the communication needs and interpersonal interactions experienced by cancer patients.<sup>1</sup>

Susan Smith is a patient at the Vanderbilt University Cancer Center who lives 100 miles north of the medical center campus. On the morning of her treatment, she calls her adult daughter to pick her up, and they drive together to the cancer clinic where they meet the patient’s brother, who lives closer to Vanderbilt. All three attend the clinic visit, and together they ask and respond to questions from the oncologist about symptoms, side-effects and a few general Quality of Life issues.

After the short visit with the oncologist, they get hugs from the nurse and ask her about the schedule for the next appointment. Before starting the chemotherapy treatment for the day, the family sits in the waiting room, and they chat with another patient who started treatment the same time as Susan. When the chemo nurse sets up the equipment for the treatment, the daughter asks the nurse a few questions about the drugs that the patient is receiving. While the patient is in the infusion room, her brother walks over to the patient support office and gets information from the social worker about possible transportation and

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<sup>1</sup> In this scenario, and throughout this thesis, both male and female pronouns are used interchangeably to signify both male and female individuals.

lodging services. The social worker helps him coordinate with a local community resource.

During the following week at home, the patient talks with a few close friends and coworkers, in person, on the phone, and on email, about how she is doing. They let the patient know that they are thinking about her and praying for her, and they provide emotional and social support. The patient's daughter and brother keep the rest of the family informed sporadically about the visit and what other people can do to help. At the patient's request, they do not give the patient's mother any details. The patient's daughter also keeps a personal journal and talks with her own friends to help her cope with the illness and care-giving.

The management of "total" pain (physical, emotional, social, and spiritual pain) and symptoms in cancer is clinically important. In an outpatient cancer clinic, the oncologists, nurses, social workers, parish nurses, nutritionists, and other clinicians each contribute an important component of the patient's care during the cancer treatment. In addition to clinical care within the clinic, cancer pain and symptom management requires sensitive communication, support, and group management among many other people engaged in the care process. Providers, patients, primary caregivers, secondary caregivers, fellow patients, relatives, friends, co-workers and others are affected and involved either directly or indirectly.

### **Research Hypothesis and Methodology Overview**

How can we create an online communication system that is accessible and desirable for all of the different players involved, and one that represents the holistic ideals of face-to-face care? How can we design a system that is effective both clinically and socially for the patient and informal caregivers? Recognizing and understanding the social roles in the patient's relationships is critical to designing a holistic online communication system. Beyond just understanding the social environment, developers must then design interfaces and functionality in the system that satisfactorily embody these relationships.

Since communication is deemed such an important need of cancer patients, the research hypothesis for this study is that an informatics system can effectively support the communication needs of patients and their formal and informal caregivers. A currently available informatics system that supports all of the patient's relationships was not found and thus initial research focused on the scientific development of an appropriate informatics-driven communication system for cancer patients. A larger study of the system's effect on the clinical and social outcomes will be conducted during the PhD phase of this research. The current phase of this research concludes with the initial user feedback and iterative design of the system prototype.

The multifaceted nature of the patient's interpersonal interactions creates a challenging problem for the design of an informatics-based cancer communication system. The system must attempt to account for the different social influences and contexts in which the patient shares and receives emotional or informational messages. For practical reasons, the interface might use the medium of the World Wide Web. However, in a web-based interface it is a major problem to design a simple and intuitive interface that appropriately includes each of the patients' communication needs.

Web-based cancer communication systems have not fully addressed the holistic context of the patients' clinical and supportive communication needs. With increased attention given to patient-provider messaging systems and personal-health records (PHRs), it is essential for the informatics community to address more of the social relationships that directly and indirectly affect the care of the patient.

The initial design of a novel informatics-based system for cancer communication was conducted in three phases (the discovering phase, the developing phase and the testing phase).

### **Phase I: Discovering: Surveying and interviewing patients and their informal caregivers**

After reviewing the literature, but before designing the system, the developer conducted extensive surveys and interviews with patients and caregivers in the Vanderbilt-Ingram Cancer Center Clinic. The purpose of this phase was to understand the clinical and supportive communication needs of the people diagnosed with cancer. The questions focused on communication needs with the clinic team, clinical and supportive

communication needs with family and friends, and general use and interest in the Internet for cancer communication.

The interviews were transcribed and were coded into a group of concept nodes using a modified grounded theory methodology along with the N6 software package that supports qualitative research. Five types of clinical and supportive relationships were identified and supported by the interviews with cancer patients and their informal caregivers.

### **Phase II: Developing: Creating the conceptual design and developing the system**

After the interviews were conducted, transcribed, and coded, several high level principles for the system design methodology were considered and defined. These ideas were influenced by the interview results, as well as by theories from social psychology and recent trends in web-based social networking systems. Focusing the design of online cancer communication systems around the interpersonal relationships of patients and families may be an important step towards designing more effective paradigms for online cancer care and support.

The prototype system was created over the course of several months with the Perl programming language and a MySQL database. Informal feedback was provided by informatics advisors and clinical advisors, as well as by colleagues and peers.

### **Phase III: Field Testing: Obtaining user feedback for rapid model development**

The application for initial user testing was submitted to and approved by the IRB. Dr. Barbara Murphy (an oncologist who specializes in head and neck cancer and who is the Director of the Pain and Symptom Management Program in the Vanderbilt-Ingram Cancer Center), her nurse, and several clinicians from the Pain and Symptom Management program were registered as users on the system. These clinicians provided educational content and were available to respond to messages from the patients. Five patients were recruited for this study, including one withdrawal. Each patient used the system as they desired for two weeks, after which a web-based survey was given about their use and impressions of the system. After completing the survey, the patients and invited family and friends were able to continue to use the system and provide feedback

and receive technical support. One patient in particular provided an in-depth case with detailed feedback, and this patient's initial use of the system is analyzed using a case study methodology.

## CHAPTER II

### BACKGROUND

A literature review was conducted with two major focus questions:

- What are the communication needs and challenges across the provider-patient-caregiver relationships?
- What consumer informatics systems currently exist to support and enhance provider-patient-caregiver relationships?

These questions are very interdisciplinary in nature, and it was necessary to search the clinical, social, and informatics literature. This review focuses on the connections between these areas rather than emphasizing an in-depth review of one particular area.

#### **Cancer Pain and Symptom Management Literature**

When creating a system for online communication for cancer patients, it is essential that the developers first have a grasp on the complex and diverse nature of the communication involved. The cancer patient has communication needs with the clinical providers, with family, friends, and co-workers, as well as with fellow patients. Reviewing the literature related to each of these relationships, it is evident that communication is an essential component of each relationship. The literature also indicates that the boundaries between these clinical and social relationships may be distinct but often overlapping in nature.

Beginning with the patient-provider relationship, there are many different informational and collaborative communication needs between the patients and the clinical team. Clinical and palliative care for cancer patients is multifaceted. The assessment and management of “total” pain (physical, emotional, social, and spiritual pain) and symptoms in cancer patients is clinically important in identifying emerging conditions and ineffective treatments in the care of the patient.<sup>1</sup> The physician, nurse, social worker, spiritual advisor, and others must work as a team and communicate effectively with the patient or caregiver.<sup>2</sup> In this environment, the clinical communication between the patient and the clinic team is very collaborative and patients have several

relationships to which they may turn for expert advice in the clinic. The holistic expertise of the care team illustrates the clinical community's aspiration to treat each patient as a whole person with complex, individual needs. In practice, many of these needs still are unmet by health-care providers.<sup>3</sup>

Communication between clinic team and the patient and informal caregivers is central to many aspects of pain and symptom management during cancer treatment. For instance, the "analgesic ladder" approach to pharmacologic pain medication utilizes a feedback loop between patient and clinician to titrate the treatment to an effective dose and drug.<sup>4</sup> Nurses play an important role in assessing symptoms over the telephone in an outpatient chemotherapy clinic.<sup>5</sup> Daily pain diaries completed by patients have been shown to be an effective medium for improving communication regarding pain management.<sup>6</sup>

Communication in cancer care can be challenging, and barriers to communication between the clinicians and the patient may exist. For example, a patient might not ask a provider for pain medicine if he or his family fears an addiction or if he wants to be a 'good' patient in the patient-provider relationship.<sup>7</sup> Ineffective communication may result in patients being unaware that there are treatments available to help with symptoms, such as fatigue.<sup>8</sup> Physicians also may need to improve their communication skills with patients. In one study of cancer clinic visits, the researchers found the conversations to be "clinician oriented", meaning that the physicians would ask closed ended questions, interrupt the patient, and talk for over 50% of the visit.<sup>9</sup> This barrier in particular is interesting with regard to the design of online cancer communication systems between patients and their physicians. Such systems may help shift the conversations to be more balanced and "patient oriented." Qualities of unbalanced face-to-face conversations may have implications towards an interface design that can help guide the conversations to be more patient oriented.

Another complexity of clinical cancer communication is that it often requires cooperation with the family or friends along with the patient. The complex nature of symptom management at home requires informal caregivers to be involved in many aspects of the treatment. These caregivers therefore play an important role in supplementing the patient's communication with the clinicians. The primary family and

friend caregivers often must coordinate care by reporting on symptoms, administering home treatments, and asking for information from health care professionals. Given et al categorize these demands as direct care (e.g. wound care and bathing), indirect care (e.g. scheduling treatments), symptom and comfort management, and information needs.<sup>10</sup>

The informal caregivers' role in clinical communication is complemented by their supportive roles in the patient's care. Family and friends can provide emotional and social support, for example by babysitting, praying, visiting, and cooking for the patient.<sup>11</sup> Caregivers often will need and seek assistance from secondary caregivers, such as their own family and friends, but these supports are not always available. Supportive activities such as these illustrate how the care of the patient blends with the patient's and caregivers existing relationships and lives apart from the treatment. Caregivers must balance their existing social roles of parent, sibling, or friend with new roles and responsibilities related to the cancer treatment.<sup>10</sup> All of these demands can take a toll on the health and quality of life of cancer caregivers themselves. Caregivers face a variety of mental health, physical health, social, and economic costs in providing care for and supporting the patient.<sup>12</sup> The social and health-related consequences of caregiving on the patient's family and friends are especially relevant to the design of online clinical and social communication systems that include informal caregivers.

The patient's social support network can improve outcomes and the patient's quality of life, but there are many factors in the quality of the support that influence these positive effects.<sup>13 14 15 16</sup> Developers of online networks for social support should be aware that the mere existence or perceived existence of an informal support network does not necessarily translate to improvements in the patient's well-being.

Given argues that more treatment plans need to take into account the caregivers' role in the care, and how the caregivers' own health may be affected by the caregiving demands.<sup>10</sup> Because oncology services overall have yet to take on a fully family-centered approach to care, it may take extra effort to design an online cancer communication system with a focus on the informal caregivers' holistic relationships and needs with the patient and care team.

In addition to communication with the clinical team and with the family and friend support network, patients also communicate with fellow patients for information

and emotional support.<sup>17</sup> Likewise, caregivers also may communicate with fellow caregivers through support groups.<sup>18</sup> Many of these support groups exist through face-to-face meetings, but electronic forms of support can be a welcome medium for peer communication. For instance, patients may appreciate being able to read about the personal experiences of other patients in an online environment.<sup>19</sup>

The communication needs between clinicians, patients, family, friends, and fellow patients combine to paint an interconnected and multifaceted picture of the patients' and caregivers' relationships during cancer. Recognizing the subtleties of these interpersonal connections is essential to the development of new online paradigms for clinical and supportive communication in cancer care.

### **Online Cancer Communication Literature**

Several informatics systems have been designed to provide patients or their informal caregivers with a portal for education, clinical tools, and social support in a web-based environment. Systems aimed solely at symptom reporting with the clinic also exist, and there are many systems that provide online patient support communities. These systems provide examples of existing strategies for several different aspects of online cancer communication for patients.

#### **CHESS**

One of the earliest systems for online cancer communication is The Comprehensive Health Enhancement Support System (CHESS), developed at the University of Wisconsin-Madison. An initial focus in the development of CHESS in the late 1980's was creating an information and communication system for patients facing a recent diagnosis of breast cancer. CHESS consists of a personalized web-based portal with integrated information services, communication services, journaling, and analysis services. The information components include an in-depth library of frequently asked questions and articles on the patient's specific illness, as well as links to other helpful online resources. The communication components include separate discussion boards for patients, families, or other topics, and an *Ask an Expert* tool that allows patients to ask a question to a cancer specialist. The journaling component allows the patient to record

private thoughts, or read shared stories from other patients. The Analysis Services include health tracking and decision support, along with other clinical tools.<sup>20</sup> As a whole, these services aim to provide informational, emotional, and social support.

Patients do not have to use all aspects of CHESS, but they can choose to utilize the aspects that most suit their needs. One recent study of CHESS with breast cancer patients at Hartford Hospital found that the social support components were the most frequently requested pages. Patients who use the social support components for most of their CHESS activity (defined as greater than 75% of all page visits for that individual) were the most active users in terms of total page requests and frequent logins.<sup>21</sup> This usage study highlights the essential role of communication integrated into an information system for cancer patients.

A randomized controlled trial conducted between 1995 and 1998 measured the impact of CHESS on the quality of life of newly diagnosed breast cancer patients under the age of 60. Through pre-test and post-test surveys, this study found that CHESS users had significantly more social support and greater competence in information-seeking than the control group. These effects were greater for women in underserved populations. The effects also were greater at the 2-month post-test than at the 5-month post-test. The researchers concluded that CHESS improved social support and quality of life for these patients, especially closer to the time of diagnosis and early during treatment.<sup>22</sup>

In June of 2003, the University of Wisconsin-Madison received a grant from the National Cancer Institute (NCI) to create the “TECC Center of Excellence in Cancer Communications Research,” with CHESS as a central focus of its research.<sup>23</sup> Several new studies at TECC focus on the idea of presence and relationships, whereas earlier CHESS studies analyzed the impact on the patient as an individual entity.

One randomized clinical trial currently underway, Caregiver CHESS (CGCHESS), includes the patients and their informal family or friend caregivers together on the system. This study will measure the effect on the patient’s symptom distress and quality of life, along with the caregivers’ coping self-efficacy, caregiver burden, and information content. Another study will analyze the impact of integrating communication with the patient’s own clinician into Caregiver CHESS, with the hypothesis that this integration will improve the outcomes more than CGCHESS alone.<sup>24</sup> As of the initial

design, the “clinician report” functionality will send the patient’s self-reported concerns and symptom levels to the patient’s physician when the values exceed a threshold or before the patient’s clinic visit. Patient-provider messaging was not included, and the clinician aspect focused on the patient’s primary oncologist and did not include the entire clinic team of nurses, social workers, and others involved in the clinical care.<sup>25</sup> These studies mark an important first step towards bringing the clinician-patient-caregiver relationships together within the CHES environment.

CHES has shown an impact on patient’s outcomes, and the Components Project at TECC is an attempt to understand which components of CHES are creating this effect. In a randomized clinical trial, one group of patients will be given the standard internet with links to external web sites. A second group will receive the informational component of CHES, and a third group will receive the informational and communication/support components. A fourth group will have access to all three of the informational, communication/support, and analysis components of CHES.<sup>24</sup> This project touches on the need for projects that break down the study of communication, information, and analysis components of online tools separately, to the extent that that is possible. The ability to break down the system into components for a clinical trial is an important part of the design and architecture of new online communication system for cancer patients.

### **CareLink**

Cancer CareLink is another online communication system that provides integrated information and communication services for cancer caregivers. Like CHES, the system is based on a architecture that can be applied to patients and caregivers with various health-related conditions. While the CHES modules first began with a focus on breast cancer patients, the CareLink architecture was first designed for Baby CareLink. Baby CareLink is a web-based system for collaboration between new parents and the staff in a Neonatal Intensive Care Unit (NICU). This system gives parents the ability to message the clinic staff, view daily pictures of their child in the hospital, access informational and online video libraries, and utilize online discharge teaching individualized for the family by the clinic staff. Baby CareLink also includes moderated chat rooms for

communication with other families on the system. Baby CareLink improved the family's satisfaction with the inpatient clinical care and it showed a higher percentage of discharges directly to the home, thereby reducing the number and cost of hospital-hospital transfers.<sup>26</sup>

The generalized CareLink architecture components include secure, asynchronous messaging, prescribed education by the clinic staff, knowledge exploration (a digital library), community collaboration with chat rooms for fellow patients and families, and data integration with other clinical systems.<sup>27</sup> One important difference from CHESS is that this framework is designed to be much more collaborative with the patient's own clinical care team, and more integrated in the workflow of the clinical information system. Initial interviews with parents of children with acute lymphoblastic leukemia (ALL) suggested that these families would desire and utilize an online, collaborative clinical communication system.<sup>28</sup> Another feasibility study by the CareLink team found that patients were willing to participate in online symptom management with their care team if it would improve their care.<sup>29</sup> The study also noted that the nurses may be more likely to follow the patient's symptoms on the system than the physician. The CareLink architecture is poised to handle this organizational aspect of cancer care, as it includes more of the clinic staff than just the primary physician.

However, Cancer CareLink is much newer than CHESS, and minimal information has been published about the architecture and initial tests at the time of this writing. CareLink's company, Clinician Support Technology, Inc. (CST), formed a strategic alliance with Eclipsys Corporation in the Spring of 2004.<sup>30</sup>

These two examples of comprehensive information and communication systems for patients and their formal and informal caregivers demonstrate that, although this sort of integration is very much in its infancy, it shows promise as a paradigm for improving the collaboration among the different individuals in the care process. They also serve as excellent examples of architectures that can be generalized to illnesses other than cancer. Rather than aiming simply to improve specific tasks related to cancer diagnosis and treatment, the driving force behind these architectures is the focus on collaboration between the people who are involved in the clinical and supportive care.

## Online Support Groups Literature

CHESS and CareLink systems are comprehensive in supportive and clinical communication with the different members of the care team. Additionally, several other informatics solutions target more specific communication challenges and needs.

There has been a fair amount of development of online cancer support groups for patients and/or their informal caregivers.<sup>31 32 33</sup> A review article on online cancer support groups found 9 articles covering 10 studies that address the needs and effects of these communities.<sup>34</sup> Another recent article reviewed 38 distinct health related studies on peer-to-peer online communication, all but six of which involved peer-to-peer communication as part of a multifaceted intervention.<sup>35</sup>

Although qualitative and anecdotal reports suggest that online support groups are beneficial for the patients' quality of life and social support, only a few of the existing studies show any beneficial effect with a large sample size.<sup>35 36</sup> These reviews conclude that more randomized-controlled trials are needed to better understand the effects and possible benefits of online support groups for cancer and other health conditions.

The beneficial effects of the outcomes studied in online support groups for cancer patients may still be uncertain, but research in this area provides much insight into the ways in which patients or caregivers choose to communicate with each other online. An analysis of 300 messages in one online cancer support group found several types of messages, ranging from sharing of information to emotional support to the sharing of humor and prayer.<sup>37</sup> This emphasis on information sharing and social and emotional support is similar to the results of other studies on the content of online support groups. These interpersonal interactions also are representative of the informational and supportive communication that occurs in face-to-face support groups.<sup>34</sup>

These studies demonstrate the potential for supportive relationships among patients in an online community. In designing an online communication system that aims to address each of the patient's social relationships, it is important for the developers to recognize the potential of including a means for facilitating patient-to-patient (or caregiver-to-caregiver) interactions. Whether it is in the form of traditional discussion forums and chat rooms or through a novel interface for online interaction, the users likely will find a way to express their informational, social and emotional communication needs

on the system. By recognizing the multifaceted nature of the patient-to-patient online communication, developers of novel interfaces can attempt to facilitate each of these interactions in the fundamental design of the interface.

### **Online Symptom Reporting Literature**

Patient-clinician online symptom reporting is another component of the CHERS and CareLink architectures that has been studied in standalone informatics tools. Recent research on computer-based symptom reporting has demonstrated that when providers are made aware of cancer patients' symptoms and preferences before a visit, they are more likely to address the patients' symptoms and concerns.<sup>38</sup> The patients in that study completed assessment forms on touch-screen computers in the clinic, and the data was printed and made available to the clinicians.

Another study analyzed a web-based tool that allows patients to self-report symptoms and toxicity levels on computers in the clinic or from a computer in the patient's home.<sup>39</sup> The system adapted common symptom assessment forms typically used by clinicians and translated them into patient readable language. Patients were able to log-in and complete the forms at any time between clinic visits over the course of an 8-week trial. The majority of patients used the system both at home and on the clinic computers before each follow-up visit, and the patients with computer access from home logged in more frequently than those who only accessed the system in the clinic. Most of the clinicians with patients involved in the study felt that the patient's self-reports accurately represented the patient's clinical status. Patients also appreciated the system and would recommend it to other patients. Overall, the study demonstrates that it is feasible for adult cancer patients (most were between the ages of 40 and 69) to report on clinically relevant symptoms during chemotherapy via a web-based system.

### **Patient-Provider Messaging and Personal Health Records Literature**

Structured, online communication between cancer patients and their clinics or physicians for symptom management is a special case of patient-provider messaging and Personal Health Record (PHR) technology. It is helpful to understand how cancer

communication systems would fit into the larger context of patient-provider messaging and PHRs. What are the current trends in these areas, and what are the concerns and challenges in implementing such systems?

### **Patient Provider Messaging**

In the realm of patient-provider messaging, there has been initial concern by some physicians that giving patients the ability to e-mail them would overburden the physicians. Privacy and security are also big concerns both for physicians and for patients.<sup>40</sup>

However, a recent study of a secure web-based messaging system has demonstrated patient and physician satisfaction and no decrease in clinic productivity.<sup>41</sup> As opposed to e-mail, a secure messaging system allows for enhanced privacy and security and workflow integration with the clinic. Also, insurance companies are beginning to consider ways to appropriately pay doctors for their time spent on electronic communication with patients.<sup>42</sup> The AMIA Internet Working Group Task Force on Guidelines for the Use of Clinic-Patient Electronic Mail presented detailed guidelines for patient-provider electronic messaging which describe the appropriate handling of patient e-mails and discuss risk-management on the part of the physicians.<sup>43</sup>

In addition to symptom management or administrative processes, electronic communication with the clinic team also may allow for the expression of emotional concerns by patients. A palliative care team described a case in which they allowed one of their cancer patients to express her emotions through emails to the team.<sup>44</sup> The emails were only one-way, from the patient to the clinical team, and allowed the team to offer the patient a sense of their interest in listening to the patient's concerns. Because of legal concerns about confidentiality and liability, the palliative care team decided to limit their accessibility to phone calls in the future. This example illustrates the potential for secure electronic messaging with a palliative care team as a means for the patients to express their emotions and concerns. With regards to the design of an online cancer communication system, there may be appropriate interfaces that expressly invite the patients to express these concerns to the clinicians, to their family and friends, or privately to themselves. For example, the inclusion of the spiritual support provider might

provide an outlet for this online “listening” in a way that fits into the existing clinic workflow.

The reported concerns of providers and patients and the existing examples of effective online messaging systems are valuable sources of inspiration and caution in designing new paradigms for online clinical communication. Lessons learned from general patient-provider messaging potentially can be applied to the design of cancer-focused interventions. Including insights from the broad area of patient-provider messaging also may help the cancer communication system generalize to other health-related domains more effectively.

### **Personal Health Records**

Personal health records (PHRs), which can be tied to a patient-provider messaging system, constitute another area of consumer health informatics that directly relates to the development of patient-centered cancer communication. Currently there is a growing interest in the concept and practicality of an electronic personal health record, controlled by the patient, which is accessible by many different healthcare providers and institutions. There are a growing number of PHRs provided by health care institutions or commercial enterprises that offer patients a secure, online repository for storing and maintaining one’s own health-related data.<sup>45</sup>

Collaborative Health Information Systems (CHIS) represents the concept of a PHR maintained and utilized by the patient and integrated with an Electronic Patient Record maintained by the providers. The development of CHIS should address the needs of all stakeholders, from the health care system, to public health, to patients, families, communities, and others. CHIS are seen as critical to empowering patients and providing quality care for patients in the near and distant future.<sup>46</sup>

Complementary to directed patient-provider messaging, PHRs represent a non-directed, longitudinal form of communication between the patient and those persons involved in the patient’s care. This non-directed “publish-subscribe” paradigm of communication allows one to publish information to a centralized repository from which approved parties can retrieve the information without an explicit request to the author. This model contrasts with the paradigm of directed messaging, which falls under a

“request-reply” model of communication. In that model, a message is sent only in reply to an explicit request by the information-seeking party.<sup>47 48</sup> This view of a personal health record as a medium of communication between the patient and the caregivers is related to Coiera’s notion that a health care institution’s electronic medical record can be a medium for conversation among the care providers as well as being a source of clinical information.<sup>49</sup> Informatics strategies for PHRs may provide insight into possible architectures, designs, and usage scenarios for new paradigms of non-directed patient communication.

Mandl, Szolovits, and Kohane propose six general characteristics of electronic medical records (EMRs) that can ensure privacy and accessibility by patients and by the other members involved in the care.<sup>50</sup> They suggest that electronic medical record should have comprehensiveness, accessibility, interoperability, confidentiality, accountability, and flexibility. These properties follow from their two main doctrines for developing electronic medical records: an EMR should be developed with open standards, such as HL7, to ensure the sharing of information, and it should be designed to give patients control over the viewing, modification, and dissemination of their records.

These principles are embodied in the architecture of the Portable Internetworked Notary and Guardian project (PING).<sup>51</sup> PING allows patients to store their data in encrypted XML files on any personal web space, and this data is accessed by interested parties through an intermediate web server. This “gatekeeper” approach to the storing of clinical information allows the patients to define access permissions and properties to each component of their data. Providers can access or modify the information as defined by the patient, and this data will be accessible by all provider or institutions. PING demonstrates the potential for the patient’s medical record to exist outside the confines of any particular institution.

Although the focus of PING is primarily on the storage and access to clinical data, this concept of a third party web server facilitating the interaction with providers may also apply to communication systems that combine both supportive and clinical components. For instance, some of the patient’s social and emotional communication with family and friends may be housed more appropriately by an outside system, but in an integrated approach, the family and friends in the patient’s support network may need

appropriate access to the patient's clinical information, and the patient should be able to share the information across these boundaries. Several aspects of the PING architecture, such as the data structures for defining the author of a document as well as the owner of that document, may be applicable to defining appropriate user-level or role-level permissions of integrated clinical and supportive communication. Using the PING model with an emphasis on communication and interpersonal relationships also may lead to new structures and models for combined electronic medical records and personal health records controlled by the patient.

### **Online Patient Journaling Literature**

Most current work in personal health records, as the name might imply, focuses on the communication of health-related information between the patient and the clinical caregivers. Online journals, or "blogs," created and managed by the patient represent a complementary paradigm for non-directed, social communication and support. Online journals are targeted more towards family and friends than towards clinical providers, but the fundamental publish-subscribe paradigm is closely related to the paradigm of personal health records.

Patients who are publishing personal accounts and stories in online journals recently have received attention in the national media.<sup>52</sup> One hospital has placed patient journals that have been reviewed for appropriate content on the institution's public web site.<sup>53</sup> While these blogs are intended for public viewing, other hospitals provide patients with web sites for posting updates on a secure web site for family and friends. CarePages is a company that allows hospitals to brand the patient's journal with the institution's name and look and feel, but the service is hosted on computers outside of the hospital.<sup>54</sup> The patient or caregiver can post updates and the family and friend support community that is invited to the site can post messages to the group. While some aspects of the site are tied to the hospital, such as the display of the facility's contact information and the ability to send electronic compliments to the clinical staff, the system is not integrated with the hospital's electronic medical record. CaringBridge is a similar, free web site that allows patients to write updates for family and friends.<sup>55</sup>

These web sites describe anecdotal evidence and testimonials to the potential benefits of online communication with the patient's family and friends. There may be untapped potential for further benefits by combining this communication with other types of supportive and clinical communication. One study of an internet based system for supportive communication between cancer patients found that the users would have liked the ability to include their own family and friends more in the online community.<sup>56</sup> Because of the many relationships involved in the supportive care process, such as patient-to-patient support and support from family and friends, it is important to examine where these relationships overlap and how these overlaps might be represented in the online communication system.

### **Blogs and Social Networking**

CarePages and CaringBridge specifically target patients and caregivers through hospital affiliations, but there are also blogging tools available for the general public that provide similar functionality. Online patient journals straddle the fuzzy border between consumer informatics systems and online communication systems used by generally healthy people. Just as it is important to understand how online cancer communication systems fit into the bigger picture of patient-provider messaging and personal health records, it is helpful to be aware of the current trends in general online journaling and related paradigms for social communication online. Many aspects of a patient's supportive communication may be well served by existing paradigms for online communication being developed in other fields. Blogging, wikis, instant messaging, and social networking systems all are examples of paradigms in the general public that may influence the design of a consumer health system.<sup>57 58 59 60 61</sup> Getting insight from how younger and tech-savvy people use online communication tools may be a significant step towards improving current and future health communication tools for future and current generations.<sup>62</sup>

This review will not go into great detail on the extensive literature in the blogging and social networking communities. The primary purpose of mentioning work in these areas is that consumer informatics may be able to follow the lead of developments in

related projects and paradigms that are not inherently health focused. Applications in social communication and collaboration are evolving at a very rapid pace. Developers and researchers in consumer informatics can play an important role in this progress by creating and evaluating new paradigms for online communication that have a strong appeal for the general public but also have inherent properties that allow for effective health communication. A consumer health informatics paradigm that can be generalized to broader communication purposes may help to facilitate the integration of the clinical and social communication of patients, caregivers and their communities.

### **Sociotechnical and Informatics Theories**

Social translucence is one theory of general online communication that can be applied to online cancer communication. Social translucence is defined by Erickson and Kellogg as having the three properties of visibility, awareness, and accountability.<sup>63</sup> The authors argue that these are critical social processes of face-to-face interactions and that they can be used as guiding principles to the design of more effective online communication and collaboration systems. For example, a person's actions in a certain situation may be influenced by witnessing the actions of his peers or superiors. Likewise, he may behave differently if he might be held accountable for his actions, as opposed to acting anonymously. One way that the concepts of visibility and accountability can be applied to online cancer communication is allowing the owner of a message to who has viewed or accessed certain information. One does not necessarily need to see the exact times and locations of each access; a simple list of the visitors to the web page may provide significant social cues that may remove some of the impersonal limitations of digital communication. The act of visiting the page is made visible to the author, and both the author and the viewer are accountable as participants in the conversation. Patients might express themselves differently when they are made more aware of the presence of the recipients of the message.

The idea of "translucence" as opposed to "transparency" is an important distinction, especially for health care applications. Balancing the accessibility of the clinical information with necessary privacy constraints makes clinical interactions often more translucent than transparent. Emotional and social support also strikes a balance

between the privacy of certain sensitive messages and the potential openness of sharing personal details and receiving encouragement from many people. The concept of social translucence may be especially apt for understanding, designing, and evaluating systems for online cancer communication.

Social Translucence as a theory for online communication is closely tied to the field of social psychology. Social psychology is defined as “the scientific study of the way in which people’s thoughts, feelings, and behaviors are influenced by the real or imagined presence of others.”<sup>64</sup> Social norms and other pressures directly and indirectly influence interpersonal actions in the real-world. Suler suggests that well-studied social psychology principles can be applied to the study of online communities and new principles of social psychology may be created to address the uniqueness of online relationships.<sup>65</sup>

Coiera also argues for a greater awareness of the social context of communication in online clinical communication systems. Interaction design theory emphasizes the importance of viewing the combination of the people and the technology as a whole when evaluating or predicting the use of health care information technology.<sup>66</sup> The social context of the health care organization is an essential factor in the effectiveness of a technological intervention. It is a two-way interaction; technology has the potential to change the culture of the organization, and the social environment will affect the manner in which the technology is used in practice. Coiera writes that “Designing the technological tools that humans will use independently of the way in which the tools will affect the organisation optimises only solutions that are specific to local tasks and ignores global realities.”<sup>67</sup> Coiera is referring to the big picture of sociotechnical influences within a health care organization, but the same idea can be applied to the social context of an individual patient’s online communication. One might say that designing the technological tools that a patient will use independently of the way in which the tools will affect the patient’s relationships optimizes only solutions that are specific to local communication tasks and ignores global social realities. In other words, the developers of online patient and caregiver communication systems should be alert to the ways in which use of the system may alter the dynamics of the patient’s social network in potentially negative ways. Even if the patient is using the system effectively and efficiently, there

may be unintended consequences on the patient's clinical and supportive relationships not explicitly measured in the system evaluation.

## **Summary**

The literature review for this research addressed communication for cancer patients and their caregivers by emphasizing the broad range of relationships involved in the clinical and supportive communication. The various existing paradigms for online communication demonstrate that there is potential for enhancing many of these relationships in a web-based environment. Like providers who want single sign on and “one stop shopping” in the workflow of their Electronic Medical Record, patients may benefit in similar and/or unique ways by having an online system that enhances *all* of their communication needs.

But such an integrated design is about more than just the convenience of a single sign-on. There also are important social reasons for the system to address the patient's different relationships. Each of the patient's relationships that are affected by the illness does not exist independently of the others. The literature illustrates many different clinical and social situations in which a patient and their informal caregivers may communicate when facing a cancer diagnosis and cancer treatment. When designing an online system that targets one or more of the patient's or caregiver's communication needs, the developers should at the very least attempt to understand the patient's other communication needs that may be affected positively or negatively by the use of the system.

## CHAPTER III

### METHODS

#### **Statement of Hypothesis**

The research hypothesis for this study is that an informatics system can effectively support the communication needs of cancer patients and their informal caregivers.

The research addresses the hypothesis through model development and rapid prototyping of a web-based communication system for cancer patients and their family and friend caregivers. The research was conducted in three phases: The discovering phase, the developing phase, and the field testing phase. Each phase built upon the results from the previous phase.

#### **Phase I: Discovering: Surveying and interviewing patients and their informal caregivers**

The purpose of the Discovering phase was to understand the clinical and supportive communication needs of people diagnosed with cancer to inform the design of a web-based communication system.

#### **Paper-based Survey Methodology**

A paper-based survey was developed to capture demographic data and to ascertain structured data on the participants' current communication practices and needs. The survey questions were motivated by the literature on patient and caregiver communication needs, with a focus on how these needs might apply to the online communication system development. Parallel surveys were created for the patients and for the family/friend caregivers, with only slight changes to the wording of certain questions. The surveys were completed both by the patient and by the informal caregivers, if present during the visit. See Appendix A for the survey forms.

One section of the survey asked questions about how the patients and informal caregivers keep track of symptoms or questions between visits, and how they remember what was discussed in the visit. These questions aim to understand if the subjects take

written notes on paper in the visit and at home, or if they tend to rely on recalling information purely from memory. The data from these questions was meant to provide details of the subjects' existing clinical journaling habits, in order to offer insight into potential usage barriers and important functions of an online journaling system.

Other clinically oriented questions ask about patient and family hesitations towards asking certain questions during the clinic visit and about the types of information and communication that the patients and caregivers desire from the doctors. These questions will provide data on what barriers might exist for certain types of clinical communication.

Before the subjects answered survey questions related to family communication, written instructions defined the meaning of "Family," "Friend," and "Acquaintance/Co-worker." Family may be defined in many ways<sup>68</sup>, and clarifying how the term is used in the context of the survey removes some of the variability in each subject's interpretation of the term.

Six questions ask the subjects about clinical and supportive types of communication that occurs with family and friends. The possible responses for each questions are presented in a 3x4 matrix: Three columns distinguish the subjects relationship to the other persons (family, friend, or acquaintance/co-worker), and four rows separate the medium of communication with each relationship (in person, telephone, email, and written letters). For each question, the subject can mark between 0 and 12 choices to indicate the breakdown of how they communicate information with each group. These questions are intended to provide more than just an understanding of the subjects' basic email or phone usage for cancer communication, but more importantly, in what ways do these mediums for communication overlap and when are they mutually exclusive for different social contexts? Recognizing how the media for communication affect one another and how the media are used similarly or differently for the different social relationships will provide insight into how a web-based cancer communication system might integrate with the subjects' existing modes of communication.

Additional questions about family and friend communication ask the subjects to list the types of relationships in which they have received emotional or practical support.

The survey also asks about how often subjects interact with their social relationships, and how often they would prefer to interact. These questions complement the earlier six questions by providing data on the quantity of the interactions and on the desires of the subjects regarding the amount of their social interactions.

The final set of questions asks the subjects to rate their desire towards using an online system for several different types of clinical and supportive communication.

### **Survey Analysis**

A full analysis of the survey questions has not been completed for the Masters study. It was determined by the author and the Masters committee that the data from the interviews (see below) provided much richer data for the model development in the existing time constraints. The survey questions will be analyzed in the continuation of this study. The survey methodology is described here because the survey was conducted in conjunction with the interviews.

### **Interview Methodology**

Along with the written survey, questions were prepared for in depth, semi-structured interviews with the subjects. The interview questions match the survey topics of clinical communication, family and friend supportive communication, and Internet usage for cancer communication. While the survey allowed for structured responses, the interview questions were open ended and gave the subjects an opportunity to respond to the questions in their own words. The questions asked the subjects to describe relevant examples of their clinical and supportive communication patterns, and this format allowed the subjects to bring up issues that were not covered explicitly in the written survey. The semi-structured nature of the interviews allowed the researcher to ask relevant follow-up questions to the unique situations discussed by each patient and caregiver. The interview questions are available in Appendix B.

### **Survey and Interview Procedures**

The subjects were recruited from the Vanderbilt-Ingram Cancer Center, with the following inclusion criteria: 1) They are patients or informal caregivers over the age of

18. 2) The patients must have confirmed carcinoma and they must be being treated by a physician in the Vanderbilt-Ingram Cancer Center. 3) They must have ability to communicate in English verbally and in writing. 4) Patients will be able to participate in the study even if they do not have a caregiver with them in the clinic.

Sixteen patients, nine of whom were accompanied by a family or friend, were recruited over the course of one week in August of 2004. The study population consisted of head and neck cancer patients recruited by Dr. Murphy, along with breast cancer, lung cancer and other adult patients receiving active treatment in the Vanderbilt-Ingram Cancer. Dr. Murphy informed the physicians in the clinic of the study, and the physicians asked their own patients if they would be interested in participating in the study. The Primary Investigator (Jacob Weiss) then described the study to the patients and informal caregivers and consented the subjects in person. The type of cancer for which each patient was being treated was not recorded.

The subjects were given the surveys to complete in the chemotherapy clinic waiting room or while the patient was receiving treatment. Each interview then was conducted in the patient's private chemotherapy infusion room with the patient and the family members or friends (if present) as a group. The PI glanced over the surveys before conducting the interviews to check for completeness, but did not spend a significant amount of time reading through the responses.

The interviews lasted between 30-60 minutes, depending on the length of the subjects responses. The interviews were audio taped for the purpose of transcribing the conversations after all of the interviews were completed. The surveys and interviews questions did not ask any identifying information, and any identifying names or information stated by the patients during the interviews was not included in the transcriptions or published quotations. Random numbers were used to assign anonymous codes that linked each survey and interview.

A total of 16 patients, along with 9 informal caregivers (of 9 different patients) participated in the interviews. All but one of the patients interviewed participated in the written survey. Saturation occurred after conducting the first 16 interviews, at which point most of the responses were similar to responses from previous interviews. The PI

and Dr. Murphy determined that conducting more interviews would not result in significantly more unique qualitative information after this point.

### **Transcription of the Interviews**

The interviews were transcribed to plain text files over the course of a month after all of the interviews were conducted. For the most part, the transcriptions contained the word-for-word responses of the subjects' more descriptive statements. Due to the time constraints, the less descriptive responses were summarized or merely described in the text by the researcher. The transcriptions of the 16 interviews totaled approximately 80-100 pages of text.

### **Coding of the Interviews**

The interview transcriptions were saved individually in sixteen text files, and these files were imported into the N6 qualitative software program. Using the N6 labeling tools, each paragraph in each interview was coded with one or more of the software's "free nodes" (as opposed to hierarchical "tree nodes"). These unordered nodes represented various concepts which described aspects of the text such as the general topic of a response (e.g. "prayer/church"), a characteristic of the response (e.g. "positive attitude"), or a specific insight about the response (e.g. "overlap of health and general life"). The paragraphs were coded with an existing node if applicable, or with a new node created to classify the new concept. Each interview was fully coded before moving on to the next interview. As new nodes were created, the earlier interviews were iterated through and labeled appropriately with the new nodes. This iterative process was not fully structured, but was guided by the researcher's recent memory of previous interviews and nodes. Although some of the earlier responses likely did not get coded with all of the new concept nodes, the researcher's total immersion in the coding process over the course of the month allowed for a relatively thorough classification in these iterations.

The author was the only coder during this process, and no inter-rater reliability was applied to the accuracy of the labeling.

After all of the interviews were coded with the software, the researcher organized the concepts into groups and subgroups with related themes. Following the structure of

the interview questions, these themes were organized by clinic communication/symptom reporting, family and friend communication, and general internet use and views.

The classification of the interviews into concept nodes was based on a Grounded Research methodology. Grounded Theory is useful when the research involves an open question about an area in which little is known.<sup>69</sup> The interviews aimed to answer the question, “In what ways are patients and informal caregivers using different communication media for cancer care and support, and how might these behaviors influence the design of an online cancer communication system?” Because few theories exist to address this question in the online cancer communication literature, this type of analysis was appropriate for the development of a design framework for such a system.

In Grounded Research methodology, a full review of the literature is held off until after the data is collected and analyzed. In the current study, the initial literature review was done before the interviews were conducted and organized in concept nodes, and this background knowledge may have influenced some of the concept labels. Also, in grounded research the interviews are analyzed during the process of data collection so that the concepts from initial interviews can be used to restructure the subsequent interviews. This study did not include analysis of the interview data until all of the interviews were complete. However, because of the semi-structured nature of the interviews, the initial insights informally noted from previous interviews influenced the direction of the researcher’s follow-up questions to some responses. In this way, the research followed the Grounded Research iterative methodology, but this process was not formalized through revisions of the structured questions. Therefore, the methodology of the interview data collection and analysis is described as a modified Grounded Research methodology.

### **Additional Clinic Observations**

While conducting the interviews in the clinic, the author observed the workflow in the clinic and informally spoke with the clinic nurse about her communication with patients. The nurse described her workflow of receiving patient telephone calls, responding to the calls, and recording the discussion as clinical communication in the electronic medical record. The nurse primarily stayed at her computer, using it as a

“home base” which she returned to after each task in the clinic. Additionally, before the interview and survey assessments, the author spent several days shadowing the clinic physicians to observe the interactions and conversations between the physicians and their patients during the visit. Observing the clinicians’ workflows and their patient relationships provided the author with a richer understanding of the clinic environment when conducting the interviews.

## **Phase II: Developing: Creating the conceptual design and developing the system**

The purpose of the Developing phase was to design and implement a web-based online communication system that embodies the high-level principles discovered through the patient and caregiver interviews and in the literature review. The methodology section for this phase will describe the author’s process of moving from a theoretical framework to an initial prototype system with a relationship-centric design approach. The methodology also includes a brief discussion of the principles from informatics and social psychology that strongly influenced the author’s development of several major components in the interface. The scope of the initial development—what functionality was included, what was simulated, and what was ignored—is described as well. The technical details of the development environment and the organizations of the database and code are presented at the end of this methodology section.

### **Moving from the Theoretical Framework to an Initial Prototype**

A relationship-centric design framework was used as the primary methodology for the design of the system. This framework for the design of online cancer communication systems was developed using the interviews with patients and caregivers, and it is described in the paper in Appendix C.

Using the model of social interactions in the relationship-centric framework, the author created the initial skeleton of the interface with an emphasis on deep functionality for interpersonal connectivity and minimal functionality for structured clinical information. The reason for choosing this direction in the early phases of the design was to ensure that the system included basic relationship-focused functionality before attempting to create structures for the complex display and capture of clinical data.

Before developing the relationship-centric design framework, the author had planned to include interfaces for charting pain, symptoms, questions, or other relevant data that a patient might track over time. While such features will have an important place in the fully developed system, creating these interfaces before creating the interfaces for representing the social context in the system could limit the users' abilities to share the structured information in ways that fully match their social relationships. The author began by designing interfaces for organizing user relationships by group or role, for messaging between individuals or groups, and for assigning flexible access permissions to any type of information. The author's effort throughout the initial development focused on keeping the interfaces for messaging in context of the interpersonal interactions on the system.

### **Developer as a generic end-user**

The author was able to design the system with a unique perspective by beginning with a generic messaging interface before targeting the clinical focus of patient, caregiver, and clinician communication. During development, the author created a testing system—separate from the secure research system—to store and share messages that related to the author's own social situation. For example, the author used the system to update a list of questions to ask his advisor at each research meeting. This question list was printed out by the author before the meeting to help the author remember the questions that arose during the week.

The author saw potential for patients to keep track of symptoms and concerns on the system between clinic visits, and this list could be printed for both the patient and the oncologist before the visit. A similar system in the research literature has shown improved communication during the visit, but this system was only used by the patient to record information on the day of the clinic visit instead of from home throughout the week.<sup>70</sup> A patient might be able to use a system to record questions during the week, and the clinicians could access this list at any point. This arrangement potentially could increase the clinicians' awareness of their patients' concerns, but there may be social issues that prevent the patients from wanting to share their question lists on the system in this way.

The author noticed that he tended to reorganize the question list just before it was printed for the research meeting, as some issues had been resolved and some questions were merely fragments of thoughts. The author did not feel comfortable with his advisor seeing the questions before he had a chance to make them clear and presentable. If the list was able to be viewed by the advisor at any time, the author would not want to use it to record his questions so freely. Although the list could be shared easily on the system, this type of question list was not intended by the author to be a medium for social communication, but rather it was a means for private self-communication. The potentially private and personal nature of question lists was not apparent until the author made the system a part of his own social interactions. One should note that the social context of recording cancer symptoms and concerns between the patients and clinicians may not actually cause these same privacy issues, and the author's personal experience does not necessarily represent the experiences of the general population. However, the author was able to experience the system in a very personal manner, which provided insight into potential issues in the system's use by the patients and clinicians.

Designing interfaces for online communication without actually experiencing the social interactions on the system can make it difficult to comprehend how the system personally affects the users. Viewing the layout of the web page and testing the interface functionality in a lab might not offer the developer this deep an understanding of the system. This method of developer testing might also be useful for other types of clinical communications systems by not requiring the system developer to be a clinician or a patient with a specific condition. This generic development also allowed the developer to receive general usability feedback from fellow graduate students who used the testing system during the development process.

In light of these unique design perspectives, there also may be disadvantages to the developer personally testing a generic version of the system. No formal evidence was found that describes a parallel between the student-advisor and the patient-physician relationships. This comparison was drawn from the author's own observations in the cancer clinic and from the interviews with patients and informal caregivers. There may be certain interfaces that work in a generic context but would function very differently for a patient undergoing cancer treatment. In this way, this method of design may actually

hinder the understanding of the system by causing misguided assumptions about the use of the design.

Another potential disadvantage of this method is that the developer over time can become a “power-user” of the system. This means that the developer may have more trouble viewing the design from the perspective of a first-time user. However, the risk of creating a design that is difficult to use is higher if the developer does not use the system at all.

### **Influences from Informatics**

The design process was strongly influenced by the communication paradigms of publish-subscribe and request-reply communication paradigms previously described in the Informatics literature. In a social context, these two types of communication architectures allow for distinct types of interpersonal interactions. In a publish-subscribe paradigm, a person publishes a message to a central source, and that message can be retrieved by any user who has access to the source. This non-directed communication allows a person to write a message without first initiating a direct interaction with another user. For situations in which a person wishes to express thoughts or record information to multiple people without having to respond to individual requests from each individual, this may be a useful paradigm for some communication.

In the request-reply paradigm a person will send individual messages in response to each recipient who requests the information from the sender. For this model of communication, the system must allow users to send messages directly targeting other individual users on the system. Request-reply may be used when a person has a question that they would like answered by a particular individual. This paradigm also can describe probing messages that have an “implied” request, i.e. where the sender of a message doesn’t explicitly request a reply, but where a reply would be expected in the social context. An example of such a message might be, “Hi, just thinking of you and saying hello! I hope you are feeling well today.” A reply along the lines of “Thank you, I am doing fine” might be expected in this situation. Additionally, the request might occur outside of the system, such as when information is requested in a face-to-face conversation, and the reply is sent in a directed message online.

These two paradigms each are useful in different situations, and an explicit effort was made during the development to create interfaces for both models of communication in the system. If functionality for one of these two models is not included in the design, then the users may not have a natural channel for certain types of personal expressions and messages.

Social Translucence, with the properties of visibility, awareness, and accountability, also influenced the design by providing a theoretical basis for the “presence” of the supportive community in the design. Breaking down the concept of presence into these three components allows the developer to systematically describe the functionality of specific interfaces for representing presence in the design.

### **Limiting the Scope of the Development**

Several aspects of development that would be part of a fully functional system were temporarily ignored or simulated for the current prototype.

### **Single Web and Database Server**

A single, secure web-server/database server was used instead of pushing the software out to all of the distributed servers that run the clinical information system. This limited server architecture allowed for the rapid, iterative design of the system with minimal administrative assistance. All messages on the system were stored in this single database server, and there was no integration with the existing electronic medical record and clinical messaging databases. Only the login process for the clinicians involved minimal integration with the existing system. The clinician’s user names were assigned (by hand) to be the same as their existing usernames, and the passwords were matched against the existing password database on each login. A link to launch the prototype system also was added to the interface of the clinical information system used by the participating clinicians. In a fully functional system, the database backend of this system would be more integrated and distributed across the existing clinical system servers. Limiting the initial development to a single server also means that all clinical and supportive messages are stored in the same database. This greatly simplifies the process of designing and testing the system, but eventually it is envisioned that the data could

exist on two (or more) distinct servers. One server would be maintained by the hospital to store the clinical information, and a trusted outside server would manage the social and supportive communication. A one-to-one mapping between the users and data objects on each system would allow the interfaces and functionality to remain similar to the prototype design. This type of fully interoperable architecture was outside the scope of the current research, but it was kept in mind in several aspects of the database design and code.

### **Integration with E-mail and the Public Internet**

The initial development effort did not allow users to share personal pages or information on a publicly accessible web site. Only registered users were allowed to access information written and stored on the system. Integration with external email accounts was included only through outgoing notifications sent from the server. The system did not provide users with an email address from which they could send or receive email messages.

### **Data structures and synchronicity in the messaging design**

The initial system was limited to plain text messages, with minimal ability to create structured clinical or supportive information. Structured fields were used for the distinct sections of a user's Personal Profile, but otherwise all messages on the system consisted of a text-based subject and body. More functionality for tracking numerical and time-based data and more interfaces for non-text-based communication would be needed for a more complete system.

All communication on the system currently uses only asynchronous messaging. Although synchronous communication may be useful in certain situations, it would require more time-commitment and scheduling demands on the developer and on all participants.

### **Clinical Team Relationships**

The clinician users of the initial prototype were limited to one physician along with the members of the Pain and Symptom Management program in the cancer clinic.

No functionality was included to determine which clinicians the patient should have access to message. A more complete system would require the ability to determine these clinical relationships when the patient registers as a user. Because only one group of clinicians was included during the prototype testing, there were no links to the patients' surgeons, radiologists, scheduling/billing, or their primary care physicians.

### **Server, Code, and Database Architectures**

The prototype system was developed using the Perl scripting language, with a MySQL database running on an Apache web server with Secure Sockets Layer (SSL) encryption. Javascript and HTML were generated by the Perl scripts. The server is located within the Medical Center clinical network, and the machine includes the Perl libraries and modules for the main StarPanel application. StarPanel is the web-based electronic medical record and clinical messaging system for the Vanderbilt University Medical Center. The server is used for the development of new applications that can integrate into the StarPanel environment.

### **Organization of the Perl Code**

The code is organized in classes using Perl object oriented programming.<sup>71</sup> The program centers around two main classes: the Object class and the Entity class. There also is a Database class, which contains all calls to the MySQL database, as well as classes for the HTML display and for the processing of web form information. The Object class contains the methods used to store and retrieve properties of any type of data object in the system. Instances of the Object class can be text-based messages, journal categories, built-in categories (e.g. "Sent-Items"), or potentially any type of structured data. The Object class allows the code to access properties common across to all data stored in the system, such as the author of the data, access permissions, and hierarchies of the data object in relation to other data objects (e.g. a reply X is a child of an original message Y). This organization makes it possible to introduce new types of structured data and automatically integrate them into the code as instances of the Object class.

Instances of the Entity class represent users and groups on the system; essentially any individual, collection of individuals, or role. A single user is an entity, and so is a public discussion group that represents a community of users. The groups one uses to organize one's own list of friends and family also are entities. This general class allows interpersonal relationships and social properties to be applied uniformly across various social representations. For example, methods for ownership and authorship can equally be applied to a single user or to a group on the system. This means that the code for sending a message to another individual is the same code for posting a message to a discussion group.

### **Database Organization**

The database also is organized primarily by Objects and Entities. Five types of database tables are used both for Objects and Entities for similar purposes (10 tables total): the Universal\_ID, Info, Access, Family, and History tables. These tables are based on an entity-attribute-value (EAV) database design. Each table contains a column for the unique identifier of the object or entity, along with a column or columns that define the type of attribute, and a column with the attribute's value. Some of the tables include a column for a second unique object or entity identifier to define joint attributes and values for the relationship between two entities/objects.

The EAV database design was used to allow flexibility during the rapid development phase, such as potentially creating of new types of structured data or new types of user roles. This flexibility comes at the cost of less efficiency in some of the database queries, especially for those attributes with multiple levels of parent/child hierarchies. The tables could be restructured in a finalized system to achieve maximum efficiency, but this was not stressed during the initial development phase.

### **Universal\_ID Tables**

The UniversalObject and UniversalEntity tables store the automatically incrementing, unique identifiers for the objects and entities respectively. The universalObject table includes pointers to the database tables that contain each type of structured object. The universalEntity table defines whether the entity is an individual

user, a group or another type of entity. These two top-level tables ensure that each Object or Entity of any kind has a unique identifier in the database.

### **Info Tables**

The objectInfo table defines properties of an object that are not directly associated with another object or entity. These characteristics may include tags of specific traits (e.g. “clinical information”), the persistence of the object (“saved” vs. “temporary”), or the general privacy of setting for the object. The entityInfo similarly defines properties associated with each entity, such as traits and roles (e.g. “patient” or “clinician”), login information (e.g. the login name and password), or the type of group (e.g. discussion forum group vs. a user’s personal grouping of contacts).

### **Access Tables**

The objectAccess table stores the read, edit, and reply permissions on a given object for a given entity. An entry with an entity ID of “-1” is used to define the default set of permissions for any entity that has the initial rights to open the object. The entityAccess table defines the general access permissions for a given entity to another entity. This is used to ensure that only entities with appropriate access permissions to an entity can access that entity’s information.

### **Family Tables**

The objectFamily table defines the hierarchical links between pairs of objects. For example, this table may record that object A is the “parent of” object B. This can represent a reply B to a message A, or it also can represent that journal category B is a sub-category of journal category A. This table is also used to record other structural links between objects, such as when object A is “saved as a copy to” object B. The entityFamily table defines hierarchical relationships between pairs of entities. An entry may define entity A as a “parent of” entity B to indicate that the user or group B is a member of the group A. An entry in this table also may define other more specific relationships between entities. Entity A may be the “doctor of” entity B, for example. The

entityFamily table is used to record and organize each user's personalized lists of family, friends, clinicians, and discussion groups.

### **History Tables**

The object History table records actions performed by an entity on a given object, such as when the entity views, creates, or edits an object. The entityHistory table records the timestamps for an entity's general actions on the system and actions performed on another entity. For instance, this table includes the times for each user registration, each login, and each time an entity visits another entity's page.

### **Additional Tables**

Objects also have an Ownership table which records the owner entity and author entity of a given object. This table also stores whether an object (typically a message) is directed to a specific entity or if it is a non-directed publishing of information. Another additional table stores shared information between pairs of entities, such as an entity's nickname for a given entity, or the list of new message IDs that one entity has in the queue for another entity. There also are separate tables for each type of structured data, which allows the system to store the actual objects in (non-EAV) relational tables with specific columns. Finally, there are several tables which store the questions, choices, and responses for the feedback survey conducted within the system.

### **Separation of the testing system**

There were two separate databases on the server for the actual research system and the generic testing system used by the developer during development. However, the code base is the same for both systems; a copy of the code is placed in a separate, web-accessible testing directory on the server. The code in the testing directory will access the testing database, while the code in the main system directory accesses the primary research database. Users with accounts in the testing database are not able to login to the research system or connect to the research database, and vice versa.

### **Phase III: Field Testing: Obtaining user feedback for rapid model development**

The purpose of the Field Testing phase was to assess the feasibility and usability of the initial prototype communication system when used by cancer patients in active treatment, their family and friend caregivers, and their providers in the Vanderbilt-Ingram Cancer Center. This assessment was needed so that the system could be redesigned based on the initial feedback and used by more patients and in larger studies. The feedback indicated how much and what kind of Protected Health Information and personal information the patients and family desired to share. The goal was to include patients and families in the early development of the system in order to answer the following questions:

1. Feasibility: What aspects do the users like in the system? What do they dislike? What are their concerns with posting treatment information? What ideas do they have to make it better? What are their views on this type of combined clinical and supportive communication?
2. Usability: What are the statistics on numbers of messages sent, logins, and usage of the different features? What qualitative feedback was provided by the users on ease of use and intuitiveness of the interface?

### **Field Testing Procedures**

#### **Inclusion Criteria**

The subjects were recruited from the Vanderbilt-Ingram Cancer Center, with the following inclusion criteria: 1) They are patients over the age of 18. 2) The patients must have confirmed carcinoma and they must be being treated by a physician in the Vanderbilt-Ingram Cancer Center. 3) The patients' expected health status over the ensuing 3 months of their treatment, as judged by their physician, would not compromise their ability to participate actively in the use of the online communication system. 4) They must have ability to communicate in English verbally and in writing. 5) The patients or their primary family caregiver must have access to the Internet from home, from a library, or from an equivalent source of Internet access. 6) The patients or

their primary family caregiver must feel comfortable using the general Internet and email communication.

The inclusion criteria for the testing phase differ slightly from the inclusion criteria for the interviews and surveys in the first phase of this research. These differences account for the longer duration of the testing phase and the requirement of Internet access to use the prototype system.

### **Recruitment of Patients**

Dr. Barbara Murphy was the contact in the cancer clinic for this study. As a physician, Dr. Murphy asked the patients if they would like to participate in testing a new system for communicating with the clinic online. If a patient agreed to participate, the PI was present in the clinic area and was introduced in person to the patient and the patient's family/friend caregiver (if present).

### **Consent and Initialization of accounts**

The PI further explained the purpose of the study and demonstrated the system on a computer in the clinic. The patient was given the consent form, and the PI answered in person any questions that the patient and the family/friend caregiver (if present) had about the system and the study.

Once the patient was consented, the PI asked for the patient's email address in order to send the message that allows the patient to initialize the account from home. The PI used a test account to walk through the different parts of the system. The PI took written notes on any aspects of the system that were confusing during this walkthrough as part of the initial design feedback from the users. No audio or video recording was used during any point of this consent and walk-through in the clinic. This process lasted 30-120 minutes, depending on the amount of questions each person had about the system and how to use it.

Before their first login to the system, all users (the patient, family and friends, and the Vanderbilt Clinic Team) were shown a privacy disclaimer that indicates the privacy and terms of use of this research system. The users must select "I agree" to the statement before initializing their accounts and logging in to the system. The disclaimer notified the

users that they must be over the age of 18 to be a user on the system. This disclaimer was based on the standard privacy and terms of use disclaimers currently used by hospital and patient communication web systems.

The users were informed that quotes from the messages stored in the database may be used in publication, but that any identifying quotes will be reported in such a way that it will be impossible to determine the identity of individual subjects.

### **Using the system and providing feedback**

After the patients had left the clinic, they were able to log into their accounts from a computer at home, work, or a public library. The PI/developer was available to answer technical questions through a “help/feedback” area on the system. All users could ask questions or offer suggestions, and the PI would respond appropriately. They were encouraged to offer feedback at any point with any ideas on what they think could improve the system.

On the system, patients can send messages to their clinic team, share news with family and friends, chat with other patients (once there are enough signed up), write personal notes or reminders, and access educational content from the clinic. The primary family or friend caregivers, who are explicitly defined as “surrogate users” on the system by the patients, are able to view the patients’ information or update the information on behalf of the patients. The family and friends invited by the patients or surrogate users are able to see the patients’ information which they are specifically given access to view, and they are able to send messages and post journals. These family and friend users do not have access to the private areas that contain Protected Health Information shared between the clinic and the patients on the system.

### **Defining a “surrogate” user on the system**

Patients are able to define other users as their “surrogates” on the system, which are similar to surrogates in face-to-face clinical interactions. The purpose of the surrogate, for this system, is to allow a trusted family or friend to read or write messages for the patients when the patients can’t easily access the Internet. Another way to

understand the surrogate role is that of a “co-manager” for the patients’ user accounts on the system.

A surrogate user can access all of a patient’s personal areas on the site, including the messages sent to and from the clinic team. The surrogate can send messages to the clinic team on behalf of the patient. While the surrogate is acting on behalf of the patient, all of the messages sent to and from the surrogate are stored in the patient’s personal space on the site, so the patient has full access to review the messages sent on his behalf at any time.

Patients can define other users to be their surrogates on the system through the web interface. This only gives those users the permission to send and receive messages on behalf of the patients *within this system*, and it does not make those people Healthcare Decision-Makers/Surrogates for clinical communication outside of the context of this system. The surrogate role on the system parallels the in-person surrogate role, but it is not equivalent to that official classification. When patients define a family or friend user as their surrogate on the system, the patients are asked to justify this selection with an online form.

### **Inviting other users**

Users (the patients or the family/friends) can invite their own family and friends to sign up for an account on the system. For example, a family caregiver may invite his or her own friends to support the caregiver and access the caregiver’s personal journals. Each user who is invited must agree to the privacy disclaimer/terms of use before logging onto the system. The users that are invited to the system by someone other than the patient or the patient’s surrogate must request permission from the patient/surrogate to access the patient’s personal, private site.

### **Survey after two weeks**

After each user has been on the system for 2 weeks, or after a major redesign of the system, the users are asked to complete an online survey, conducted and stored within the system itself. This survey asks basic demographic questions and questions about general Internet usage. It asks the patients to describe their thoughts, ideas, and

hesitations towards using the system for clinical and supportive communication. The users are asked to be available to be contacted for feedback on subsequent iterations of the design. These surveys are tied to the users' accounts in the system, and so the responses are not anonymous to the PI. This allows the PI to view the survey feedback in context of the users' previous questions and their actual use of the system, in order to best utilize the feedback for refining the system. The survey only is given to the patients and the users that are invited to the system by the patients or the patients' surrogates.

### **Data Analysis**

The qualitative analysis involves the user feedback/questions asked through the system, the free-text survey responses, and the types of messages sent on the system. For this study, the feedback is organized by general themes and applied to the continuous redesigning of the web site.

The quantitative analysis for this study involves basic statistics on the number of logins, number of messages sent, and values of other basic usage parameters. The qualitative feedback is the primary result for this stage in the research, and the quantitative analysis only includes relatively basic statistics.

During the testing phase, the majority of the feedback and usage came from a single patient, her clinicians, and her family and friends. Because of this small sample size, a case study methodology is used as the framework to present these results.<sup>72</sup>

### **Security of the Database**

The database is stored on a secure server within the Medical Center, on one of the servers used to store other secure StarPanel projects. Only the research team has direct access to the database on the server. Like StarPanel, the system is accessed by the users through a secure web connection with the standard encryption used for most web applications.

### **What types of users will be invited to use the system?**

The users of the system consist of the following types of people:

1. Vanderbilt-Ingram Cancer Center (VICC) clinical team members
  - These are the clinical team members that would access the patients' medical record in StarPanel/StarChart, or the team members who see the patients in person. The patients' oncologist is the primary clinical user, but the oncologist's clinical team members that work with the patient also are given accounts to handle certain types of communication with the patients (as is done in the real-world clinic). These users include:
    - The clinic nurse
    - The clinic nutritionist
    - The clinic social worker
    - Other members of the VICC clinic team who play an active role in the in-person care of the patient.
2. VICC patients
  - The patients are the primary subjects of the research study. The patients, or the people the patients define as a surrogate, are able to use the system to communicate with the clinic team and with family and friends. It is the patients' Protected Health Information that will be shared in the messages on the system.
3. Family and friends invited by the patients or surrogates
  - Patients or surrogates are able to invite other family or friends to use the system to communicate about the patients' treatment or general supportive communication. Patients or surrogates are able to assign permission to groups of these users so that they can view and respond to the patient's selectively shared information. For some of the users, the patients may choose to only share the most general information about their condition.
4. Other family or friends invited by family/friends
  - Family or friends that are invited to use the system by the patients are able to invite their own family and friends to use the system to share emotional or practical support in the caregiving process.

**If there are users on the system that the patient doesn't explicitly invite, how can the patient control which users have access to his personal site on the system?**

Through the web interface, patients can limit their personal sites to only those users to whom they or their surrogates give permission. There are several types of users on the system that a given patient does not directly invite. There are other patients using the system, and those patients may invite their own family or friends. Likewise, the family and friends invited by the patients may invite other family and friends to use the system.

Being invited to use the system by family or friends does not automatically give a person access to the patient's privately shared information. These users only are given access to the inviter's personal site on the system. If the new users want to view the patient's personal site, then they must request permission from the patient through the system. This allows, for example, a patient's sister to invite her own friends to use the system to support the sister in coping with her role in the caregiving of the patient. All users have the ability to share their own personal journals or messages. Patients may choose to allow other patients access to their own personal sites by inviting or confirming requests from those users.

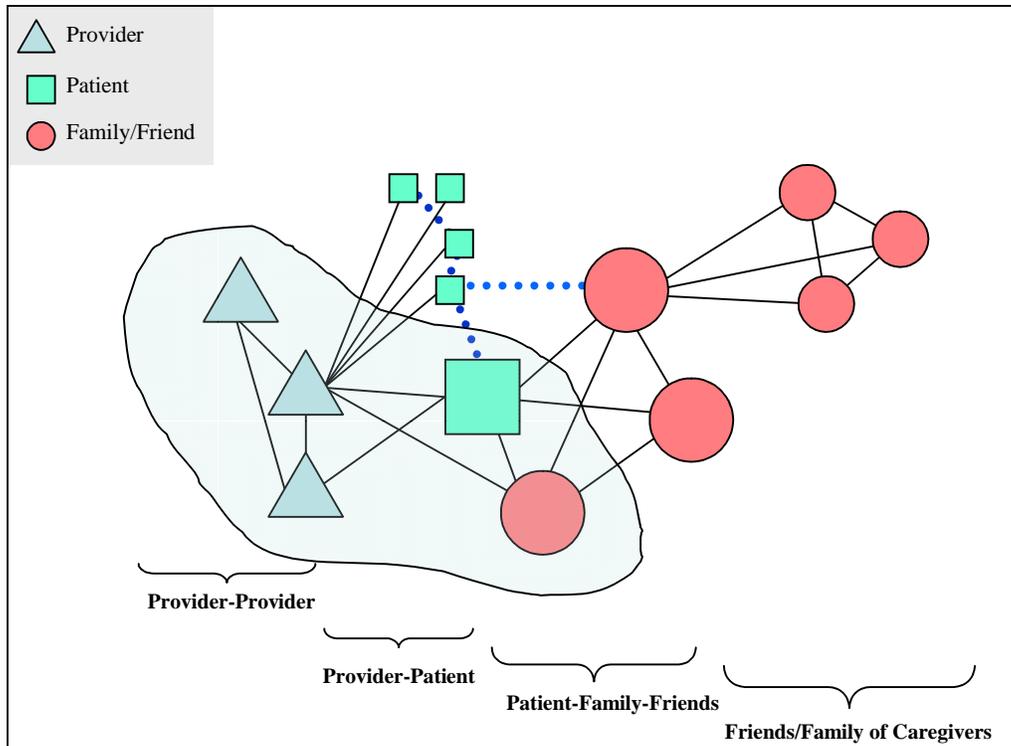
**How can patients control which Protected Health Information (PHI) sent by the Clinic will be shared with other users on the system?**

The clinical information shared with the patients by the clinic team has additional privacy protections to keep it from being shared with family and friends without the patients' explicit permission. Messages containing PHI that are sent from the clinic team are placed in secure directories on the patients' sites to which only the patients and the designated surrogates can access. To prevent unintentional release of the information in this directory, the patients are not allowed to open these directories to other users.

Patients or surrogates may choose to copy some of the messages sent by the clinic team to another directory that is accessible by family or friends. In this more accessible directory, the patients still have control to limit access to only the users or groups that the patients assign access permissions. This allows the patients to be in control of each piece of PHI that they choose to share with selected users on the system.

Patients may also write their own messages and journals for family and friends that contain the amount and type of PHI that the patients wish to express. Patients may limit access to these messages, but it is ultimately the patients' choice about what they want to write. If the patients want to write about PHI that they do not want shared with family or friends, they can put it in one of the secure "clinic team only" directories, or in a "private" directory to which only the patients and their surrogates have access. In general, the patients have the ability to create private directories and limit the content within each category only to a defined subset of users or groups on the system. Users who do not have access to certain content do not have any indication that that category or content exists (it is "invisible").

Figure 1 represents the different types of people that may be users on the system. A "cloud" is drawn around the clinician-patient-surrogate team. This cloud represents the "clinic team only" communication space, in which messages are shared securely between the Vanderbilt-Ingram Cancer Center clinic and each patient. Any users outside of this boundary cannot view or access these messages. Patients may copy a specific message from their personal clinic space to one of their directories that lives outside of this boundary, but this does not affect the security protecting the rest of the messages within the boundary.



**Figure 1: “Clinic Team Only” Communication Space**

### **Login Security**

Users must log on with their unique usernames and passwords through a secure Login page. Each unique login is tracked in the system, as are other actions performed in the system. These logs can be examined if there is any concern of inappropriate usage of the system.

### **Types of PHI shared by the clinic team**

In order to minimize the risks of accidentally or maliciously sharing private information on the system, only certain Protected Health Information (PHI) are sent by the clinic team. The patients’ entire medical records are *not* being shared on the system. Again, this PHI is shared in the “clinic team only” area to which only the patients and surrogates have access.

Messages between the physicians or clinic staff and the patients are the primary type of information shared in the system that would constitute PHI. Other specific types of PHI also may be shared with the patients by the clinic team. The types of PHI potentially may include:

- The name of the patients' physicians in the cancer clinic and important phone numbers
- The patients' specific cancer diagnosis
- The patients' specific type of treatment being received in the Vanderbilt-Ingram Cancer Center
- The days that the patients are scheduled for a visit or treatment in the clinic

This information may be provided for the patients to use for their own reference, and it is also intended for the patients to be able to share these details with certain friends and family if they choose to do so. The patients are able to share specific PHI messages with certain users and still limit the actual clinical communication with the clinical team to themselves and their surrogates. The interviews conducted with the patients and family suggested that many patients choose to be open about this basic information with their friends, family, and acquaintances. The patients are not required to share any PHI with family and friends, but the system provides the patients with the means to copy and share their PHI when they want others to be able to read it.

## CHAPTER IV

### RESULTS AND DISCUSSION – PHASE I

The Phase I results illustrate the clinical, supportive, and online communication of sixteen cancer patients and nine informal caregivers. The transcribed interview responses were labeled with 73 non-hierarchical concept nodes using the N6 programming software. The listing of these concept nodes can be found in Appendix D. Several of the larger concepts were divided into multiple sub-concepts, and some of the original concepts were combined into broader concepts.

The interview responses are presented in the general order of the interview questions and grouped by themes elicited from the identified concepts. The interviews were conducted with both the patient and the caregiver together, and responses from either party are classified using the same set of concept nodes. The total interview counts for each concept do not distinguish between a patient and a caregiver response. However, in the synthesis of the responses presented here, special attention is given to examples which involve the communications needs of the caregivers. Due to background noise in the recorded interviews, parts of the responses were inaudible and the quotes are presented with ellipses to represent these gaps. Ellipses are also used in place of the interviewer's interjections or to join a series of responses together. The interview questions are available in Appendix B.

#### **Clinical Communication**

##### **Tools/Methods for keeping track of symptoms and concerns**

The first section of the interview seeks to learn how patients and caregivers keep track of their symptoms and concerns, and how they express these issues to the doctors in the clinic.

### Written Question Lists

In ten of the interviews (n=10, 63%), the patient and/or caregiver used written notes to record questions for the doctors between clinic visits. In some cases the questions are kept in a notebook or journal (n=5, 31%). Other times questions are more temporary and written on a “scrap” piece of paper (n=4, 25%). The scrap of paper ranges from a small card in a wallet or a notebook, to a piece of paper that is discarded after the visit.

One patient mentioned that keeping questions on a scrap piece of paper does not provide her with a sense of continuity of her symptoms during her treatment:

[...] just on a little notepad-no I do not retain those ever after I've seen the doctor. So I have no continuity [...]. I probably would go back and do that if I kept-or if I had the journal or some sort of data. I'd probably go back-that way I could go back three weeks and say 'ok, well this week I had this problem and this problem and this problem that I'm not having this week'. Where as it is right now, I guess-[...] time I finish this, I'm probably gonna go 'look, I wonder if felt this [...] before?' or something [...]. So I'll have no record of [...]

The written questions are not always used actively during the clinic. The lists might instead be used more for backup, as in the following two examples:

I usually kept it in my day timer, but this time I didn't have my day timer with me, I just had a little card [...] It's just a scrap piece of paper I can pull out and put in [...] folder. So, if I need to. A lot of times I don't though.

There have been times when my brother wasn't remembering everything, so I wasn't making too much of a deal of it, but I was making a habit of, if I would see him or if we were talking, and I detected something-usually I remembered it and didn't have to go back to them-but I did start taking notes and I started keeping a little piece of paper in my wallet that-if I thought I was gonna forget something between visits. [...] And we hadn't really discussed this, but I've been keeping notes since almost the beginning of this. Last few visits haven't been as necessary, because we're getting better in that regard, but I've relied on notes a great deal. [...] Usually I didn't end up needing to use the notes. I would check them just before I came in, and I'd realize I had recalled. I had them with me in case I needed to. Not on this visit, [...] the last few visits, and up until then, almost every time.

The first example above is from a patient, and the second is from the brother of a patient who is actively involved in the clinic visits. The patient's brother in this example, as well as another caregiver and a patient, also described the use of mental notes or cues in remembering questions (n=3, 19%). The one patient said that he does not write a full question down on the paper, but just writes a "one word reminder." The caregiver brother explained his method of using mental cues during the visit:

I guess I've tried to create some mental cues sometimes. I would relate [...] one aspect of his visit, so that would prompt me to remember it [...] Usually that works. [...] I'll try catch the mental cues, 'well she's gonna check this or she's gonna ask this' and that should be my cue to remember this or that.

The involvement of the brother in writing notes and question lists illustrates how the patient's family and friends can be involved in the clinical communication. Creating the question list may also be a collaborative process between the patient and the family or friends. One patient described that he sits down with his wife and they both come up with the questions to ask the doctor during the visit. Another patient who works as a nurse described the role of her co-workers in helping her come up with a list of questions to ask the doctor:

The very first time I went to the doctor, when I first found out that I had breast cancer, my friends and I got together, my co-workers, and we made a list on what to ask. [...] Because I was real nervous and upset, because I just found out, and then I was gonna be seeing her pretty soon, like the next day or so, so it was real helpful to have them help me fill out a sheet of papers on what to ask.

### **Charts and Numeric Logs**

Only two patients (n=2, 13%) mentioned keeping any structured charts or logs of their symptoms. One patient also has diabetes, and so he had practice in keeping active records of clinical values:

I have diabetes too, she [his wife] keeps a running log. And after every chemo treatment I sit and talk with her about the size [...], what Dr. \_\_\_\_\_ tells me. We keep pretty good care of it. [...] And then now, that we are going through the cancer, we kind of keep a record of it too. I'll jot it down. She keeps it in a little book, one of those spiral notebooks. [...] She's starting to keep all that on the computer, so that she can reference it

[...] quicker. [...] I carry a laptop with me, and a lot of times I'll just jot it down on my laptop, and she'll download it at home [...] My wife is a stickler for keeping records. Everything. If you don't write it down, it didn't happen. [...] Well, the diameter of it. It's moved from close to my [...] to down [...], so it's moved that much, plus it's dropped about four-I think it was [...] to start with and it's down to four something. [...] [The doctor] measures it here, and then I just tell her.

The other patient keeps a notebook with very detailed charts of her symptoms and her fluid drainage, which she brings to show the doctors:

I usually write it down: the date, the time, what's going on as far as what symptoms I'm having, or if it's a fever, what my temperature was. Frequently, that's been-my experience has been fevers. Or I've had a rash from medications and different stuff like that that I've needed to call about. So just basically, I'm keeping track of what the symptom is, and/or what level it is.

[...] I've got drains in right now, so right now they want to know how much fluid are they draining and when I'm emptying the drains and everything, so I have to keep that, and it's much like just a graph kind of thing. I just use columns-the date column, the time column, the amount column, the right or the left, you know, that kind of thing. [...] I do that, usually, two to three times a day, whenever I drain these, it depends on how full-and the time and the date. So they know how frequently I have to empty them. That tells them when they can take the drains out.

I do everything symptomatically. If I'm not having any symptoms, I generally don't write anything down. But if I'm having symptoms, I do it several times a day, usually maybe every 2-3 hours, or that kind of thing. [...]

### **Personal Journals**

In addition to tracking clinical symptoms and details, four people (n=4, 25%) mentioned that they also keep journals of their personal emotions or general observations during the treatment. The patient who charts the details of her drainage and symptoms mentioned that she also writes in a separate, private journal:

I keep a journal, actually online, that I just go and use for my general how I'm feeling, emotional more. [...] It's on one of the drug companies web sites.

One patient's friend described how she kept a personal journal when her own mother was going through cancer treatment, and she would write in a journal about her feelings:

[...] 'I'm mad as hell and that I don't believe there's a god', and things like that. You feel that way, though. I did when my mom was diagnosed, I felt that way, and I wrote it down in my journal, but I didn't go tell everybody that.

The daughter of another patient described her journaling techniques related to her mother's treatment:

She comes every day of the week. So, I have a journal that I personally write down myself. I don't do it every night, but when I do take time out maybe every other day, I go through what happened throughout the day, and I get the report of the afternoon when she comes from her radiation treatment [...] just write in my journal What we went through, what we experienced, her pain level-and there's not a lot, that's a good thing. [...] the healing process, so we know what to expect on [...] part. Other than that, I don't keep her type of a journal like they do on a daily, hourly, weekly [...], but I keep my own. And I refer back to it, just as I would-she was not feeling this way one day, but she's feeling better this day [...] I go into detail, what she says and how she's progressing. I go into detail about everything, I don't leave nothing out, I don't leave nothing to chance. I don't want to second guess anything.

### **Reporting Symptoms and Getting Questions Answered**

The patients and caregivers in twelve of the interviews (n=12, 75%) indicated either that they really have not had much pain or symptoms or that if something new does arise, it is easy for them to remember without writing it down.

Right now, I'm symptom free, to tell you the truth. No pain. No other symptoms. My blood work's been good [...].

Luckily, I haven't been that sick that I've had to do a lot of that. The chemo hasn't destroyed my brain cells so much that I can't remember most things.

There's not a whole lot to it, just stay on the same regiment she's in. And that's a good thing, 'cause it's easy.

I can just remember when I feel bad, that's not a problem. Or when I have a headache, or-some of the medicines make me have a bad headache.

However, in ten of the interviews (n=10, 63%) the patients or caregivers suggested that understanding and communicating about the treatment becomes easier with practice or that they had more questions at the beginning of the treatment.

When I first was told I had cancer, I was on [the Internet] almost every day until I found the answers that I wanted. Now, maybe once a week or so, I'll go back and check to see what's going on, new things that come up.

Trial and error. You experience it, and then you begin to know. This is my 3rd treatment. Now I know a lot more what to tell the doctors and the nurse now than I did then. Because of what I've experienced-I see what they're trying to do.

I've been doing this for two years now [...] Really it's, you know, I pretty much got it down now where I know what I want to ask them.

But now I've got all my questions answered, or most of them. You know everything's real scary at first, and you've got a thousand questions at first. Then once you get used to it, and what's gonna take place, you know, then it's not as-you don't have as many questions. I know what she just gave me, I didn't have to ask her.

These responses indicate that the patients and caregivers go through a gradual learning process in knowing what to expect during the visit and knowing what to ask the doctors. Yet, they still may have some questions about the treatment process that they have a hard time getting answered as much as they would like. The family and friends in particular have needs in getting their own questions answered, especially if they aren't able to attend the visit in person. Thirteen of the interviews (n=13, 81%) included a description of the family's or friends' own communication needs related to the patient's treatment and support. Family and friends may have a need to understand specific details of the treatment procedures and clinical care plan (n=7, 44%), or they may have questions about cancer in general or about how much support the patient needs.

The patient who was accompanied in the visit and interview by his brother had experienced clinical issues for which the brother needed more information from the doctors. The brother described this situation:

We had some nutrition issues though when he first-about the time he was finishing up his treatments that made me think we had missed some instructions during that period of time, because it didn't seem like we were fully compliant. [...] Well, I came back, and we asked a lot of questions, and we made some notes and found out exactly what he should be doing for his nutrition. Got him on a schedule. And, so he has his schedule, and he does that for himself now.

[...] And when we would talk on the phone, I was under the impression that he had a schedule, was going by it, and was on track. And then, later on, I looked and discovered that he only thought he was on a schedule and on track, that there was a lot of medicines that hadn't been enough used, and he wasn't getting as much food in. And, so that told me I needed to be asking him more specific questions [from] the doctor. And he wasn't doing quite as well as I thought he was at the time.

Patients recognize that the informal caregivers may have questions about certain aspects of the treatment even when the patient does not have a strong desire to know the answer. One patient mentioned that "the only thing I have trouble getting done, is getting my wife's questions answered." There are some questions that he does not want to know or need to know, but his wife wants to know and he respects her desire to know. He explained that his wife is more concerned than he is about the treatment. Other patients described similar communication needs:

[...] Especially my son [...] will go, 'well what about this?' or 'what about that?' And I said, 'you didn't-' I said, it doesn't concern me, but if he wanted an answer, he needed to tell me.

But if there was a format that they could go on, and if they have a specific question that-regarding my prognosis or whatever. If they did not want to come out and ask me directly, for whatever reason they might have. It would be great if my immediate family could contact the doctor [...]. I mean, I wouldn't have any problem with that.

While the more involved family members may have questions for the doctors, some of the family's questions and concerns are more general about the cancer, or concerns can arise out of a misunderstanding of what the patient desires. The friend of one patient described how it can be hard to communicate with the patient from a distance:

I think the web site's nice for people who-I think people, when you're sick, are so afraid of bothering you, because they don't know how you're healing.

You hear-you see on TV all these horrible stories about chemo, and cancer, and everything. And some of it really is, but I think people are so afraid-she has a new baby, and she's going through all this stuff, and her husband's taking care of her, and I just don't want to bother her. And I mean-I would feel like that too about somebody I didn't know real well. [...] I think I've misunderstood a lot of things, just because I-you know, just trying to respect her privacy, and her recovery, just not called as often as [...] - or gotten as much information as I could. Usually when I talk it's more social than physical and how's all the treatment going. You know when you found out there was a second tumor, I didn't know that."

Another patient described how it seems that certain friends may feel guilty and they might try to do more to help than the patient desires. He described how one friend wanted to help and insisted that she take the patient out for pizza, even though it wasn't something that the patient wanted to do. He added, "I'm glad that they're in standby, but I wish they'd be in standby" [...] "You can't be active, supplying a non-needed need. That's just a fact." This misunderstanding by informal caregivers of what the patient desires and how the patient feels is echoed by another patient and his wife:

[...] The word cancer scares everybody to death. You know, '\_\_\_'s got cancer' and they go <frightened sound>, like it's a death sentence. Yeah, at first I think everybody was just very-well, first of all, they were surprised because he looked so good. I mean, there was shock there, shock factor. And then [...] they were, you know, kind of ginger about what they said and how they said it. But then [...] he had his surgery, and [...]

The patient added that they tell other people to "ask anything you want to" and the patient's wife added that "It scares everybody, and that's a natural reaction I think." Examples such as these illustrate some of the questions and concerns that the family and friends may have about the patient during cancer treatment.

### **Confidence in Vanderbilt**

Overall, the patients and caregivers expressed confidence in Vanderbilt and the clinicians who work at Vanderbilt, and they feel that the doctors and nurses do a good job in answering their questions (n=11, 69%):

I think the nurses here do a wonderful job of answering questions. I have asked them, here.

I'm glad to be out here, I would not take her nowhere else. Nowhere. This would be it. As far as getting information there for me, there's not a problem.

I'd rather rely on something that Vanderbilt says this is a good source of information on this kind of cancer, this kind of treatment option, as opposed to trying to stumble across it.

Yet, some of the patients and caregivers (n=4, 25%) mentioned that they realize how busy the doctors at Vanderbilt must be in caring for all of their patients. In three of these four interviews, the patients indicated that this may be a reason why they may try not to overburden the doctors with their information needs:

I'd just try to deal with it, or wait until I come in to see the doctor again, to ask her, just because it's just hard to get to them sometimes. They're busy [...] I'm not the only person in the world.

So, that's what made me think of, you know, like a video of just some preliminary things of cancer. How you might have gotten it, all those questions you're gonna have that are gonna waste the doctors time, because none of those questions are going to bring the doctor closer to, you know, really healing you.

I would like to make myself available to people who are about to go through this... So terrified, didn't know what was happening. As wonderful as the doctors are, they're busy people and don't have time to baby-sit you through this whole time. Their job is to make you well.

The fourth patient suggested that because the doctors are so busy, she would be fine with either the doctor or the nurse responding to her question:

I would prefer just to email my doctor, as opposed to call. [...] Email the nurse or doctor and just expect a reply by the end of the day. [...] I'd rather just [...] the doctor and the nurse at the same time, and whoever gets to it first could reply to it, and answer my question. Or call me, or whatever, on their leisure. [...] Because, they're so busy out there, they are so busy. I'm just amazed. [...] of patients that they see here.

## **Role of Nurses**

This account of the nurses' role in answering patient questions was reflected in other patient and caregiver responses. In six of the interviews (n=6, 38%), patients and caregivers mentioned that they communicate with nurses in addition to the doctors to get answers to questions. Nurses may work very closely with the patient during the treatment, as one caregiver noted, "We've pretty much had the same nurse [...]. And, so, she knows him well."

One patient said that he might call the nurse or clinic staff if it's not urgent enough to contact the doctor. Additionally, other patients and caregivers provided examples of how they communicate differently with different nurses or doctors (n=4, 25%). The patient who keeps detailed charts of fluid drainage and symptoms describes how she has different communication needs with her different doctors:

Because I see different doctors that need different information. So, where Dr. \_\_\_\_\_ is more concerned with my fevers and infection and that kind of things, and what symptoms I'm having from my medications, Dr. \_\_\_\_\_ wants to know how much I may be draining from my drains. [...] He's my surgeon. So, my oncologist versus surgeon they want to know different things. He doesn't need to know so much what my fever is, more that he needs to know what's going on with my surgery site.

## **Patient-to-Patient Communication**

In addition to getting questions answered from the clinic staff, the patients and caregivers in seven interviews have learned, or would like to learn, what to expect during the treatment from experienced patients (n=7, 44%).

But, talking to the patient that's went through it, knowing about what they're gonna do in the chemo room, that seemed to help me some. Just, mainly just knowing that, well they could get through it, I can.

I would like to talk to someone who's had that same procedure. It's important to talk to someone who's had the same thing done... it cuts down on the surprises.

Especially, to be able to get information from somebody that has something I have.

I've had a coworker that's had lung cancer that has shared a lot of his experiences with me, which [has] been quite helpful.

Likewise, several patients expressed a desire to help other patients learn from the patient's own experience (n=4, 25%). One experienced patient described how he was put in touch with a new patient through a staff member in the clinic:

[...] customer patient relations or something like that. She pulled me aside one time and said, 'a guy came in and had the same thing as you, he's your age, and he's befuddled about the whole thing.' And I said, 'well, call me.' I gave her the phone number and said, 'have him call me.' And I guess about maybe four or five days or week went on and then he called, and we talked, and I told him everything I could without assigning my symptoms to him. It might not be the same. I said 'call me anytime if you want to talk about it,' and I haven't heard anything.

Several patients (n=3, 19%) specifically mention that in talking to other patients, they want to learn or share specific information about the cancer, or "sharing real knowledge" as one patient put it.

But about his illness, the cancer, not for the personal, but about his illness [...] we can talk about the cancer, who has the same type of cancer. We can discuss, we can hear about how good or...

In the quote above, the patient and caregiver want to learn more about the patient's specific type of cancer. Similarly, another patient was hesitant about talking to other patients, because he said they don't know about his situation. The need for more information about the patient's specific type of cancer or the patient's specific type of treatment (from other patients, from Vanderbilt, or from other sources) was mentioned in seven interviews (n=7, 44%).

### **Communication with Family and Friends**

The next part of the interviews asked the patients and informal caregivers about how they keep other family members and friends informed of how they are doing. The interviewer also asked what kinds of support the patient have caregiver have received from other family or friends.

## Privacy Levels in sharing and receiving information and support

Six of the patient and caregivers (n=6, 38%) expressed a general openness in sharing information about the patient's treatment and progress.

I go into details with everybody. I don't even want them to be guessing. You know, I want them to know. It's not something to be ashamed about. I don't think [...] it's none of their business, because it is. [...]

[...] That's why I wanted to make it easy, you know, because there's other people that have passed on the web site, and there's-people reading all-people I don't even know reading it, because they've passed it on to prayer groups and things like that. [...] No, I don't mind when people pass the link on.

I don't try to keep anything from anybody. If they call and ask how [...] I don't want anybody to think that there's something to hide. There's not. [...]

Including documentation. The opportunity to consolidate information and being instant and being available to all interested parties. We've so overdone this privacy crap-and why? Because the damn media.

In eleven of the interviews (n=11, 69%), the patients and caregivers described examples of how they give different amounts of information to different groups or individuals.

Maybe with immediate family, my sister, or maybe her mom and dad, but just immediate family. Other than that, I'd have to pick and choose who I want to know what's going on.

[...] Say I'd send it to the two oldest ones, and the two youngest ones, I might send them something else. It's just what the information is, how much they want to know about... [...] They're still-one of 'em is nineteen and the other is twenty two, and [...], no sense [...] burden them, but the two oldest ones, they want to know what's going on.

Right. 'I allow my daughter or my brother to have access to any of my records [...]' Sure, I wouldn't have any problem with that' [...] "Yes, I think I would probably want to have that kind of specific-just because, I'm kind of a private person. And, you know, I wouldn't want uncle Joe Shmoe in Cleveland-there is no uncle Joe Shmoe in Cleveland-to just be able to jump online and go 'oh look! [...] click click click'. I really would prefer not it to be open access. Closed access. Or limited access, maybe that's what I [...] to say. [...] I don't have a problem with a general, you

know-‘much improvement in symptoms this week, blah blah blah, was able to eat solid food’ [...] started eating solid food last week, man, I’m so excited. But anyway, yeah, limited, but not detailed. [...] Yes, one group has access to anything I can know myself, and one group has access to general knowledge, yeah, I would go for that. [...] Yeah, there would be probably be some, where I would probably [...]. I would probably, just say for example with my daughter, I would tell my daughter more pertinent details or some things that might be going on with me, just as-how these drugs affect my whole body, that I might not feel comfortable sharing with, like the Joe Shmoe group.

[...] To the people you go to church with, you wouldn’t want to say things like, ‘I’m mad as hell and that I don’t believe there’s a god’, and things like that. You feel that way, though. I mean, have you felt that way, because I did when my mom was diagnosed, I felt that way, and I wrote it down in my journal, but I didn’t go tell everybody that. So there are things that you would share with your family or your close friends on a web site that you might not share with your church members. Things that you wouldn’t say, but you feel, and you need to get out. So, those kind of things.

Now, friends, I tell them everything. I don’t tell my brother everything, cause I don’t want it getting back to my family. I don’t want to tell them, I don’t want him to tell them either. I don’t want them involved. It would be a pretend sincerity on their part. I had an aunt who’s husband died of cancer three or four years ago, and-he had lymphoma. And I was telling her everything until something I asked her not to tell anybody got back to my younger cousin. [...] told my mom and my mom told me. So for a while I wasn’t telling her anything, but then the other day when I was speaking with her, she suspected that I was hiding something. She’s pretty-she’s perceptive. So, she knows everything. And ordinarily I wouldn’t be telling her everything, it just bothered [...] a little.

### **Explicit Support**

Each of the interviews included examples of how family or friends have provided support for the patients and caregivers in various ways.

Examples of emotional support were mentioned in ten interviews (n=10, 63%):

And some of my closest friends, have not only just given practical help, but they also give emotional, psychological boost as well, especially my boss.

She’s been the rock behind me that’s enabled me to go through it alone.

I remember one time I emailed my Jazzercise class, you know, when I first was diagnosed [...] in the middle of the night [...] pouty [...] so I said, 'I know I can't call you guys right now' it was like three o'clock on the morning, but, you know, 'this is how I'm feeling about all this, and I just thought I'd let you know,' that type of thing.

Examples of practical support were mentioned in thirteen interviews (n=13, 81%):

My next door neighbor, he runs a lawn care service. Since I've been taking this, a lot of the time on the weekends, I don't feel like mowing the yard, he's been mowing it for me. He won't take any money for it. [...]

I have a friend that lives down the street, [...] she called me up one day, and said, '[...], this is what I want to do for you. I want to coordinate food.' And at first I was like, 'oh, no' and now I'm like, oh that would be a blessing in disguise, because that way she could-what I did, is I gave her the contacts, and she contacted, like, my Jazzercise group, and she contacted-and then they spread the word. [...] the day care group, and she contacted and spread the word. People at work, she spread the word. She got a list of people, and she keeps [...] and she schedules people when I'm ready for food. And [they'll] bring it to her and then she'll bring it to me at the end of the day at dinner time. So that's worked out nice.

Examples of informational support were mentioned in eleven interviews (n=11, 69%):

I'm an internet user for work purposes [...] news and other updates and things like that anyway. Since [the patient's] had cancer, I've also used it to do research [...]. I forward it to him. Even some of the sources of-we've had to look at some financial resources, assistance and things of that nature. We've found some of those things on the internet.

A lady across the street from us, [...] is a cancer survivor, so she's offered-you know, asked us if we need anything. She's given me her magazines and materials pertaining to cancer, I think the magazine is called Cure. She's got a big pile of [...].

Examples of social support was mentioned in four interviews (n=4, 25%):

[...] Usually when I talk it's more social than physical and how's all the treatment going. [...] *[this is the friend of the patient]*

[...] my friends will call me up saying, 'hey, do you want to go out to dinner or something'. Or '[...] with me right now. [...]

Additionally, different types of people in the support networks were discussed in terms of their involvement and communication in the clinical and/or supportive care. The roles of the spouse or immediate family were mentioned or demonstrated in twelve of the interviews (n=12, 75%):

No, but if my kids think I'm not telling the truth, or you know, that I have the story wrong, or whatever, they'll jump in and say 'why is blah blah blah' [...] If somebody asks something about me and they don't like what I said or I don't remember, then they add in the answer.

I only come on Mondays with her for this treatment, and the rest of the week my husband comes with her [...] [*this is the patient's daughter*]

The roles of the other relatives and friends were mentioned or demonstrated in all sixteen of the interviews:

Well, mostly my family that I email, my dad and my uncle and everyone that's kind of farther away from me. I just let them know how my treatment's going and how I feel in general, and, you know, that kind of thing, just to keep them updated. [...] I do that maybe a couple of times a week.

Acquaintances, I wait for them to call me. And, family and friends, they either call me or I call them.

But yes, I spend a lot of time on the phone with various members of my family, with my friends

I have three brothers and three sisters. Usually I'll call three or four of them, and they spread [...]. They call the other ones.

The roles of church members were mentioned in seven of the interviews (n=7, 44%):

[...] people that we go to church with and stuff. Mostly, I have a few friends. Usually they'll call, and I'll see 'em in church. I have a few that call. [...] Yeah, find out where I'm doing. I got one guy that calls me every day from church. [...] sometimes that he doesn't call, I'll call him. You know, he's gonna try everyday. But mostly, I just- sometimes my pastor, he'll call. [...]

We have a prayer chain, and the lady has her email-I mean she has an email address, and then she emails-she sends me the email telling me who's on the prayer request. Then if I want to send her something back, telling her about my chemo or whatever, I do. [...] and then they email other members, and it's a chain that keeps going [...] I just let them know how I'm doing, when my next treatment is.

The roles of coworkers and employers were mentioned in five of the interviews (n=5, 31%):

I'm constantly in touch with somebody. A lot of 'em is at work. We have good emotional support from my job." "[...] people I've worked with that are concerned, you know, they want to know. They should know, because that's my family. Really that is my family. That's the closest family I've got [...], so that is my family. [...] And we treat each other that way. It's good to have a good rapport with anybody, but to have it on the job is another thing. To be as close to your supervisors-so if you do your job right, and you're not just there to get over [...]

Yes, my boss at work has come to visit me every week, and he lives about 25 miles from where I do. He's always come to see me, and if he doesn't, then he always calls on the telephone.

The family and friends of the patient's own family and friends were mentioned in six of the interviews (n=6, 38%):

So many people were so concerned about what's going on. Even people who didn't know her, who were friends of mine, and [...] people who maybe met her once at one of our parties. How's she doing? What's going on? And I just say, why don't you check her-here's her web site, you can read [...].

[...] her sister-in-law, and now she also knows somebody else that is going through it right now, and then, of course, my ex-mother-in-law knew a lady that had survived breast cancer, and she got her to call me.

People who he worked with when he worked with the same company I do years ago, some of them have sent me questions asking for an update by email once in a while, and I responded to their emails [...] *[this is the patient's brother]*

## **Implicit Support**

In addition to explicit clinical and supportive communication with the family and friends, the patients also have certain types of implicit communication even when no actual information is exchanged.

Prayers may be a form of implicit two-way communication, such as when someone prays for another person and when that person knows that someone is praying for him or her. When asked about communication needs, one patient responded, "Prayer." The importance of receiving prayers and putting someone on one's prayer list was mentioned in five of the interviews (n=5, 31%).

We have a prayer chain, and the lady has her email-I mean she has an email address, and then she emails-she sends me the email telling me who's on the prayer request. Then if I want to send her something back, telling her about my chemo or whatever, I do. [...] You want all the prayers you can get.

'How you doing, I'm doing good, ok, glad to hear. You're on my prayer list, etc. etc.'

I always tell her, keep him on the prayer list.

Another form of implicit communication between the patient and the support network is the sense of knowing that the family and friends are there for the patient. Even if the patient does not have any active need for support, they know that these people are thinking about them and are willing to help. This type of implicit support was mentioned in eight of the interviews (n=8, 50%).

Well, we know, when we ask, they will come. That's the kind of friends that we have. And also, they know too, when we need it [...]

That's really the important thing [...] especially with families, you know, they care and they are interested [...]

They'll let me know that if we need anything, or if there's anything that we need, don't hesitate to ask. You know they'll be there, just call them on the phone, you know, and they'll come by and ask her if she needs anything. They just offer it out of generosity.

You know, they're there if I need 'em, and I know it. I've had a lot of people offer to help. And they have helped [...]

The presence of the online community in web-based communication is another example of implicit communication. One patient who has a personal web page on which she shares treatment and family updates mentioned,

[...] I want to do a counter out there, [...] And, cause I was curious to know how many people are going out there. [...] Because I really would love to know, how many people are going out there.

The standard personal web page does not include automatic feedback to let the patient know who is reading the updates, and the patient perceived the absence of their presence in her interactions with her readers. Similarly, the friend of another patient knew someone whose child had cancer, and the parents used a web-based system to write updates to family and friends. The family and friends also could post supportive messages to the site for everyone to read. The friend described how this feedback mechanism allowed her to feel more connected to the patient's support community:

One thing you get to see how many other people have been on that site and have replied in a positive way, and we're praying for you, and this and that, and I can help you do this, or whatever. I think that's a good thing." [...] "you know, sometimes they write and say my child has the same thing, or my wife had this, or whatever, you know. So that's kind of helpful [...] that there are other people that go through things, even if you're not the patient or the patient's family or whatever, you just know that there's other people there and they're supporting these people

### **Holistic Aspects of Communication**

There are aspects of the patient's and caregiver's communication with family and friends in which clinical communication blends together with the supportive and social communication. There is a holistic quality to the patient and family communication; the different types of communication interact with each other and they cannot necessarily be treated as isolated events.

In seven of the interviews (n=7, 44%), the patient or caregivers mention how they have to coordinate the clinic treatment schedules with other schedules:

Sometimes there's a complete breakdown at the last minute, because it's just like, I'm really-I'm supposed to have somebody with me when I come in for my treatments. [...] my daughter was supposed to be with me today,

[...], her mother in law was going to baby-sit, got called in [...], which means she couldn't come. My brother who comes with me a lot, is on his way to [Louisiana]. So today, I'm here by myself. If I had known, I could have sent a blanket-well, I probably could if it occurred to me anyway-sent a blanket email saying, 'I've got-this has happened. I need someone to take me in tomorrow, somebody, [...]y'all get back to me and let me know what you can work out' or 'can somebody take me and somebody come and get me?'

Well, we have a calendar, we write everything on the calendar." [...] "squares for each date, you know, and we write ..." [...] "they're laying carpeting next Tuesday, so that's on there. I take the sheet they give me today, and I'll put it on [...].

The only time I missed work, coming for a treatment. They've been pretty good working with me, you know, time off. [...] I try to give them as much notice as I can.

They are working my schedule around her. I found out what days-she would be down her on Mondays. [...] I went to my supervisor, and in turn he went to his supervisor. I gave him that excuse with all those dates on it, which was every Monday to the end of this month that I would have to be here. It was not a problem, you know, they were very understanding. And if I needed-which I was this past Thursday, because they changed her radiation from that afternoon to that morning at nine o'clock. So my husband worked around that. He was taking his time off, I took a day vacation, but now he's changed to third shift in order to be here. So yeah, it's not a problem.

One time, they were gonna bring me salad [...] because they had some kind of dinner-luncheon at church. Of course, I wasn't home, and I wasn't home for hours, so they didn't get to bring it.

In addition to coordinating schedules, eight patients or caregivers (n=8, 50%) described other ways that the cancer communication interacts with other types of communication. For instance, the daughter of a patient who keeps a detailed journal of her mother's treatment and clinical progress also writes about her own personal life and studies in the same journal:

Oh yeah, it's my journal. It's my journal. It's my composition, what goes on with my life, just different things that happen. [...] My whole life, this is my journal, and she's my life.

The daughter's writes about all aspects of her life, and the cancer caregiving is just one component of her life. This example illustrates that the caregivers may have a need to keep their own personal notes or journals. In four of the interviews (n=4, 25%), the caregivers have kept personal notes or journals about the patient's health, a mix of the patient's health and their own health, or about their own personal life and emotions.

Another patient described how she communicates with her brother about her treatment over the telephone:

Because, especially my brother, he likes that voice to voice thing a lot. But still, you know, we could talk about other things, instead of all of this. I mean, don't get me wrong, this is important, and it's really a big factor in my life, but it's not the only thing I want to talk about. So if I just would cover the other [online], and then if the doctor has a specific something or other that needs to be shared with the family, you know, that could be done too.

This example illustrates a potential concern of the cancer communication overshadowing the other types of communication that the patient desires. The patient who writes updates on her web page for family and friends indicated that one mode of communication might affect other modes of communication in undesirable ways:

Usually, like, immediate family, like parents will, or sister in laws or someone they'll call, then my husband will communicate with them, or I'll communicate with them. But for everybody, in general it's the web site. I'll put entries out there, and people kind of read up on it. So that way, you know-but what I've noticed is, no one ever calls. Everybody's so afraid to call [...] You know [...] call, come over or you visit.

It seems to the patient that people just read the web site instead of calling her on the phone, even though the patient would like to talk on the phone and visit with these people.

### **Comparison of Media for Communication**

The interview responses provided insight into the advantages and disadvantages of both email and the telephone for clinical and supportive communication.

Twelve of the interviews (n=12, 75%) offered reasons for why either email or the phone is preferred for communicating with the clinic:

I think there's not anything I wouldn't ask over the phone. The problem is [...] using the phone, the place closes down at five o'clock. To be able to use the keyboard, the computer, and ask a question and somebody'll be able to answer it before tomorrow.

“[...] I know that any time I could pick up the telephone and call, but with the telephone you always have hold and the waiting period. And sometimes they can't find the person you need. To me, something that I could go to my computer, email, I think that would be great.

[...] usually, if you-well, if it wasn't something you needed immediately [...] if you had a problem, [...] I think it'd be more quick on the phone [...] it'd be immediate.

And if I run out of a prescription or-I can email the nurse. [...] I emailed her yesterday, because I had a prescription run out. [...] Well, I tried the telephone first.

Sometimes they don't, sometimes they do, you know, but it seems like if you leave a message, the nurse doesn't call you back.

[...] It would [...] expedite everything if everybody did that. There'd be no other, you know-there might be more dead end questions, where people are asking a question just to ask a question on the Internet, which may at some point in time bog down the doctors, but I think that would be a really, you know, [...]

[...] If I'm at home, I'll call her, and I have not have had any trouble as far as getting through and getting questions answered.

Normally I don't need to take notes or anything, if everything's fine. When I start experiencing symptoms, I start writing it down. What's going on, when it started, that kind of thing, so I can tell my doctor. Usually, it almost always happens after hours, so I'm calling in to the person on call. But, for the most part, that's been pretty effective, just my keeping a running log of what's going on.

I would prefer just to email my doctor, as opposed to call. You sit on hold for ten minutes, and then a person will come answer the phone, 'well who do you need?' 'I would like to [...] talk to my doctor's nurse, cause you have to go through the nurse' 'sure, hold' Hold, hold hold [...] talk to the nurse, 'ok, we'll call you back'. Email the nurse or doctor and just expect a reply by the end of the day. [...] I'd rather just [...] the doctor and the nurse at the same time, and whoever gets to it first could reply to it, and answer my question. Or call me, or whatever, on their leisure. [...]

In thirteen of the interviews (n=13, 81%), the patients or caregivers gave examples of situations in which email is the preferred mode of communication with family and friends:

People I work with find it easier to just be able to send a quick email than try to get on the phone, which is always monitored on the job. So the emails are not really monitored too much, as the telephone conversation. [...] It's just only after the treatment, because otherwise I would see them everyday on the job. But after I started all my treatments, then it came down to mostly email. [...] It's always easier for me to work with email than it is with the telephone. [...] Just that part of my job, I was a receptionist to a telephone switchboard operator, and when you get through talking, answering about, anywhere from a hundred fifty, two hundred phone calls a day, you find it a pleasure just take care-email without having to talk to somebody.

Now one thing I thought of, in some cases, some links I emailed him, I could've called him and said 'if you want to get on and get to such and such, you can' [...] And so when I'd would call, I would say 'don't talk anymore than you can feel like'-this kind of thing, so from his perspective-I'm just trying to place myself in his perspective I can say, my throat, if it was hurting me to talk, yeah, I'd rather exchange emails.

But yes, I spend a lot of time on the phone with various members of my family, with my friends, I feel like they-[...], because I end up saying the very same thing to everybody, in general. And then if I forget to say something to somebody, and explain this particular problem, and then I'll say something about the problem's better, and they'll be like 'well, you didn't tell me that'. So if I only had to do it one time, shoot it out to everybody, 'here is the daily update', that would be great.

Fourteen of the interviews (n=14, 88%) suggested that the telephone is the preferred method for communicating with family and friends in certain situations:

Well, we're a very small family, for starters. Just two brothers, and our mother. My wife. And then the next closest is cousins, and then it starts getting much more distant. So, there aren't a lot of us. So the number of people we would talk to as far as family is a very limited number. It's, we're either there or we're close by or a telephone.

As far as email, our emails are just 'happy birthday'-if anything urgent, it's the phone.

It depends on if it's-like I've got relatives in Oregon and Maine; can't see them, so we communicate by telephone. Acquaintances, I wait for them to call me. And, family and friends, they either call me or I call them.

Like, there's things I wouldn't write out there-I wouldn't write things about my [...] or the emotion of it. [...] Like, I was crying last night at midnight, you know this it the times that I've called my friends for support. Because there's people from work reading it. And I don't-you know? [*the patient referring to her web site updates*]

A few of the specific reasons why email or the telephone is preferred relates to the emotional or subjective qualities of the conversations. Two people (n=2, 13%) mentioned that email makes it easier to compose one's thoughts carefully, while the phone makes it easy to say things without fully thinking them through.

[...] It's easier-you can take your time and do your emails, get everything just exactly the way you want to say it, and then send it. Whereas-like over the telephone, it may not always come out the way you want it, by that time you've already said-if you haven't had time to really think that much about your answer.

Three people (n=3, 19%) mentioned that they or their family members like the telephone because they prefer to hear the other person's voice.

[...] so, just pick up the phone. And it's nice to hear the voice, feeling. You know, you don't have [...] nothing feeling [...], you just type in and send it.

You know, there's not too many people out there that don't use the Internet. I'm really a rarity. I can't type, that's why I-[...]. I'd rather pick up the phone and hear somebody's voice than read and write it on the screen.

Three people (n=3, 19%) also said they prefer the phone because of the synchronous conversation and the ability to add things in or ask clarifying questions.

[...] use the phone. You get answers right away, email you have to wait for the answer, you know. [...] phone, you can ask and the answers come back right away. [...]

I prefer talking on the phone, cause I like to add stuff in [...]. Doing it through email didn't bother me either.

On the other hand, six people (n=6, 38%) mentioned that they try to keep the conversations brief and to the point, either on the telephone or on email. Email can make it easier to accomplish this goal in some situations:

Yeah, to me it is. Sit down and type out and email and send it, [...] move on to something else. [...] I'd rather do that than talk on the phone, because there's always some other things they want to talk about, you know, I [...] really got time for it, time is too short.

[...] I'm not one to spend much time, you know, I get what I need done and talk, and get off.

I could improve on my response mechanism that wouldn't evoke follow-ups that would not be convenient. If you can put it in an email, they know. They can respond if they want to, I don't have to read it if I don't want to. I don't have to lose any time.

My brother doesn't ask question, he interrogates me [...]. On the phone [...] but it's easier on email. [...] On the phone, when you tell him something, then he'll come back with two or three questions, [...] picking apart what you've already told him, and you reach a level where, 'beats me, I don't know'. [...] He's that way with everything. [...] he would make a study of it. On email, I can usually just kind of brush it off, because you don't get that immediate response.

Some of the advantages and disadvantages of email and the telephone relate to the logistical aspects of the conversations. For example, two people (n=2, 13%) mentioned that there are financial advantages to using email instead of the telephone in certain cases ("Phone calls cost money, web doesn't"). The person's ability to type fast and use the computer also might lead that person to prefer one mode of communication over the other. Three people (n=3, 19%) said that they prefer the telephone because they can't type fast. Six people (n=6, 38%) indicated that typing at computer can make it easy for them or their caregiver to record and access information.

Because I tend to use the computer a lot. And I don't have any objection to the old-fashioned writing method. I do write things, and I'm a big reader. And that's just kind of one of the things with the computer too, because I do so much on it. So, but yes, I would be more inclined to maintain a daily record, if I had something already there to work with. [...] I mean, like I said, I have my computer on most of the time anyway. Sometimes it's just such a hassle to go find where is the notepad, do all the things that it [...], let me write this down before I forget. [...]

In two interviews (n=2, 13%), the patients or caregivers suggested that email or web-based communication can limit the degree to which they have to repeat information over and over for different people.

[...] You know, that would be so much easier to be able to update everybody one time, instead of having to say that ninety gazillion times.

[...] That's why I wanted to make it easy, you know, because there's other people that have passed on the web site, and there's-people reading all-people I don't even know reading it, because they've passed it on to prayer groups and things like that..

You know, with somebody-[...] So many people were so concerned about what's going on. Even people who didn't know her, who were friends of mine, and [...] people who maybe met her once at one of our parties. How's she doing? What's going on? And I just say, why don't you check her-here's her web site, you can read [...].

In six of the interviews (n=6, 38%) the patients or caregivers indicated that symptoms or fatigue can make it hard for the patient to talk on the telephone. In some of these cases, email is preferred when talking on the phone is difficult. For example, one patient who has speech difficulties related to her treatment said that it is almost always easier to use email and that a lot of people have a hard time understanding her on the phone.

Sometimes it is, it's just not very convenient-very good time, convenient to talk. And sometimes I'm just not feeling well enough to really want to have a prolonged conversation with somebody.

There are times that I do write up an email and I will send it to several people. And that is probably something I'm going to get more involved in. I had some computer problems, and my computer was down for a little. So I kind of got sidetracked off of that. But I probably will be increasing email back-and-forth usage. Considering, I have cancer of the throat, and there are those days where my throat does bothers me a lot, and I really don't want to talk a lot. [...] Yeah. Sometimes I-I mean, I get tired holding the phone to my ear. That sounds stupid, but that's how tired this makes you. Sometimes you don't even feeling like [...] the phone [...]. Just go to the computer, send, I'm done, I [...] lay down.

## Using the Internet for Cancer Communication and Searching

In eleven of the interviews (n=11, 69%) either the patient or a caregiver had searched for cancer information online.

I've gone into a web site to National Cancer sites, and I found out more information about my particular type of cancer. [...] When I first was told I had cancer, I was on there almost every day until I found the answers that I wanted. Now, maybe once a week or so, I'll go back and check to see what's going on, new things that come up.

Cancer.com, WebMD, there's a couple other sites that I've been to. [...] I do a Google search or something like that. [...] A couple times a month, I guess.

My son has looked up and shared information. I don't know the exact sources, but he always comes up with different sources [...] I think you can find whatever information you need, so if you've got a question [...]

I've gotten on there looking for resources. Especially starting out, when I didn't know where to go, or why to go there, that kind of stuff.

Six of the patients and caregivers (n=6, 38%) indicated that sometimes there is too much information online and that it can be hard to find information related to the patient's specific case.

I've logged onto the American Cancer Society on the internet, but sadly they didn't have as many answers as I really would like for them to have had in my case. I guess, general type of things that most people would ask, but in my case I needed to ask more specific questions which their web site's not capable of answering. [...] Some of the side effects of the radiation treatment. They explained what radiation treatment was, and the technical aspects, but they never told anything about what the side effects were or how long you might have those side effects. It just didn't go far enough into depth, the detail is to certain things.

[...] Cancer Society. There is so much information out there [...], but I don't think anybody knows that they're out there. We're being treated here at Vanderbilt, we should be able to get on our status as far as the treatment's concerned. And then kind of get a picture of what the treatment is doing to it, and how well it's going [...]

[...] If I could go without having to search-searching the web sometimes for specific cancers, sometimes, especially medical, you get a lot of generalities, where if there were a specific site that she had that dealt with the specific things that I'm dealing with or chemo that I'm dealing with. I would use that tool. [...] Right. You know, these are the real things-cause you know yourself there's a lot

of stuff out there. You don't really know what to honestly believe. Where, if there was something and I could research my condition through say, a web site for Vanderbilt clinic, then I would be much more inclined to use that tool than I would be just to take my chances on what I might surf out there

The National Cancer Center has a lot of information [...]. Sometimes almost too much (laughing) [...] "Well, you have to choose this and choose this and choose this [...]. And really, like now, I'm not interested in everything, I'm just interested in [...]. And so sometimes it's a little bit hard to find what you're really looking for. And then his cancer is a little bit unusual too, and so it's not a whole lot of information [...]

In three of the interviews (n=3, 19%), the patient or caregiver has received information related to cancer from family or friends via email.

[...] they found something out there that I didn't know about, and they'll email it to me. [...] I know a couple of my friends that they're computer junkies, and they're on the computer constantly. They'll find stuff and email [...].

[...] I have a cousin [...] she sends me a lot of stuff [...] email [...] Well, she bundles it all up.

In six of the interviews (n=6, 38%), either the patient or the patient's family and friends used computers and the Internet frequently for general activities and communication. Additionally, in four of the interviews (n=4, 25%), the patients or caregivers had used online tools for cancer communication, primarily for journaling and supportive communication. One patient wrote about her feelings and emotions online in a private journal provided by a drug company's web site.

You can design it pretty much how you want it, color-wise, page color-wise, type color-wise. You can play music while you're-they have different types of music for you to listen to while you're journalizing, or whatever, so it's very nice.

Another patient's husband created a personal web-page for the patient to post updates about her treatment, her family, or other aspects of her life.

Most of my emails, most of my entries, are funny. You know, like, I try to write funny things, like about the new vacuum that my sister in laws bought me because mine was puffing smoke out [...]. I was so excited, they bought this [...] and I had to express that out on the web site [...]

So, and there was a point where I wasn't even gonna talk about the mastectomy on it, but like, people are gonna know about it, you know, or they're gonna wonder. They're gonna say, 'what [...] surgery are you having?' You know, I'm gonna have surgery, that's what I was writing out there, and [I get this email] 'what kind of surgery are you having?' so I said 'Oh well!'

I like the web site, because people will go out there on their leisure, and read it. [...] If someone new gets hold of the web site, they can read everything [...]

So on the main page is where all the entries are for me. But over towards the side, we have the picture of my husband, a picture of me, [her children]. You click on the heads and that's how it goes to each site, but mine is the first one that pulls up. But you can click on me and it will also pull that up. But I click on [her child] and I've done her updates there.

One patient mentioned that he has emailed the nurse in the clinic when his prescription ran out. Another patient's church has an email-based prayer-chain to which the patient can send prayer requests to the community and also receive prayer requests from other church members. The friend of this patient described another friend's use of an online journaling system when that friend's child had cancer.

Well, there were a lot of people that did go to the web site, especially my family because we knew the family [...]. Every day her mom would put something on there, unless things were really bad and her mom just couldn't sit down and do anything. She would tell about her doctors visits, her surgery, just in general how things were going. How \_\_\_\_\_ was tolerating everything. You know, sometimes you didn't want to read, you hate it to-I mean, sometimes I would hate to even access that page and look at it, because I look-you know I was gonna read that \_\_\_\_\_ had died and stuff. She was three. But then on the other hand, it was good, because you could email them back, let them know you were praying for them, let them know what you had read.

You could reply on the web site, yeah, you could. But last time I replied to \_\_\_\_\_, I replied to her personal email though. But, you could reply to the web site itself, and everybody's reply was posted on there for, you know, everybody else to read. Kind of like, she was saying about the chain type thing that everybody's reply was there, that you could reply that way or personally, however. [...] Yeah, to see what other people are saying, is that what you're asking? What other people have to say, and what they're offering. I don't know, just to know how many other people are there. You know, and if they-you know, sometimes they write and say my child has the same thing, or my wife had this, or whatever, you know. So that's kind of helpful that you that there are other people that go through things, even if you're not the patient or the patient's family or whatever, you just know that there's other people there and they're supporting these people.

Really from dealing with the web site, I thought it was a really-I did think it was a real positive thing. Because-I'm sure it was for \_\_\_\_\_, some days I'm sure she didn't want to write, and she would say as much. You know, I'm not up to writing today, and I'll update everybody in a few days, or stuff like that. But I think, the whole web site itself was just a really good thing, and having experienced that, it made you feel good that you knew that you were keeping up with somebody and that you were praying for somebody that, you know, that you could actually read about, and they weren't just, you know, I don't know, a figment or something. You know, it was a real person. She had pictures on there, and everything. It was a good thing.

### **Views on a potential web-based cancer communication system**

Eleven of the patients and caregivers (n=11, 69%) described how they think a web based system for family or clinical communication might be used.

[...] I would certainly use it. I would use it. I just [...] with the computer anyway, and I use calendars, and prompts and alarms and everything else to keep my schedule going. So I would probably use it.

I think a web site would be [...]. It gets the patient involved in the treatment itself, and you have a better handle [...] what's going on as far as the treatment's concerned [...].

I'd like to see a lot more of it. Because with chemo there's so many different doses that they give, that, for this type of cancer I've got, [...]. I think it'd be a good thing though, like [...] 'this is what's gonna take place. If you're getting this type of chemo, this is what's gonna take place.'

Yeah, I'd be interested in that. Like I said, I think computers are great. I don't use mine as much as-in as many ways as it's capable of being used. But I'm always looking for new ways and things and ways to improve everything.

Lab report would be good, if they could access it.

If I thought it would hurt me, I wouldn't do it. If I thought it was to be helpful, I'd like to know it. So why should I put myself in a box.

Eleven of the patients and caregivers (n=11, 69%) also gave reasons why a web based system for family or clinical communication might not be used in certain situations.

And probably a lot of the patients would-I've met a lot of patients here though, who probably wouldn't know how to use it.

The reason I'm hesitating is that it hasn't come up that we needed to. I suppose if we needed to, yes.

More with the doctors I think, than friends. If I was having a lot of pain or whatever, and it went on for a couple days or something

[...] or if I had recurring illnesses, then I might have been more inclined to look on the web, but I had no questions unanswered here. [...] I'm not trying to be [...] the site. I don't have too much time left, I don't think, you know, and I'd rather spend it reading a book than learning to use [...]

No, like I said, really it's, you know, I pretty much got it down now where I know what I want to ask them, and like I said, you know, we pretty much take care of it every trip; works out pretty good." [...] "I could learn to use it. But I don't know how much I would-I don't usually [...] on the computer much, but I could learn to use it.

It's just sometimes I'm better at just picking up the telephone and calling somebody than I am actually going and getting on my computer. Yeah, that's all.

Probably not. I would probably-well, I would say something different to you than I would say to you. And I'd really rather just [...] in person. I'd rather do it in person, rather than just post it on the web site for them to find out. [...] we don't have to do a lot of communicating that's not in person. [...] They live in Memphis and we live here, so it's not like they're halfway around the world. Now if they were in Europe or something, it might be a whole different story. [...]

The privacy and security of a web-based system was a concern of six of the patients and caregivers (n=6, 38%)

Depends on what kind of information they want to set up your-personal information. [...] If they want a social security number, or, you know. We've had some identity theft. A nightmare once it gets started.

Eight of the patients and caregivers (n=8, 50%) offered specific suggestions and ideas for features in a web-based cancer communication system.

[...] In thinking about what may be the direction of this, had there been the ability to log those concerns, and maybe even go back and check something off if it was no longer a concern. I don't know if-I can't speak for [the patient], but I would make use of that.

I think an F.A.Q. section for various radiation treatments. Maybe even something that follows a logic tree. Ok, it's my head, or it's my throat, and here are the frequently asked questions that apply to people who are receiving treatments through their throat, or through their head. I'll bet some of those that are-come up over and over and over again. Things that- 'It'll be about three months before you really start feeling better', we just got-we found that out today. There are a lot of those things. Not being able to concentrate clearly for a while, that's a common thing that you could put down there. Then they'll want who you [...] from your doctor or your triage nurse [...]

I'd definitely like to see a web site [...]. to be able to see something on the screen that's tailored to me. This is me, this is what they're doing to me, my lab results, and how am I doing as far as my lab [...] My appointment and treatment schedule. If I could pull it up on there, and verify, yeah this is the date that they told me. Or if I lost the appointment sheet, I could pull it up and see when my appointments are. I think that would be good.

Well I usually do try to write something down-very concerned about-down as it occurs. But then there's also that [...] that sometimes I have done that and then I've walked out and left that laying on the kitchen counter. But if that information was already to the doctor, then it would in there, and she would say 'I see here that you had [...] we need to address' So, I think it would be great.

I've been offered rides, and pretty much, 'what can I do? Tell me if there's something I can do.' If there was something that I could already have set up that says, 'ok, week after next, I've got to have somebody come and go with me. Could you work out with \_\_\_\_ [...], who can help me out?' That would be a good thing.

Would be a place where I could actually go into my own record. Only in a specific place, and make those comments, like we're talking about, saying 'this problem blah blah blah, I'm having this reaction blah blah, please flag for us to discuss this' [...] The patient should not be able to alter anything on the record. But a space that I could go in for patient comments, or ongoing history, or general reactions-something like that would be excellent

So, that's what made me think of, you know, like a video of just some preliminary things of cancer. How you might have gotten it, all those questions you're gonna have that are gonna waste the doctors time, because none of those question are going to bring the doctor closer to, you know, really healing you.

I like the instant messaging, on some of the web sites where you're trying to do a technical question, and you get out there, and, 'hi, my name is... I'm ready to answer your questions now' Or you're in the cue-5 minutes, and they come up and say 'ok, I'm ready. What's your question?' you know? That's pretty cool.

I would like to talk to someone who's had that same procedure. It's important to talk to someone who's had the same thing done... it cuts down on the surprises.

## **Discussion of Phase I Results**

### **Clinical Communication**

The methods for recording information and remembering questions may influence the design of a cancer communication system in several ways. First and foremost, the role of the family and friend caregivers in this process can be recognized in the system. These results demonstrate that the family may assist the patient by keeping their own notes and journals. Written questions can help the patient and caregiver organize their thoughts before the visit, even if the written list is not necessarily critical during the visit. The family and friends also may actively collaborate with the patient in preparing question lists and recording symptoms. If a clinical system for tracking and recording information is designed only for use by the patient, it may limit the family's and friends' assistance in these areas.

There seems to be less use of structured symptom charting, and more of a need for organizing the questions and observations about the treatment over time. Numeric data was kept by a few of the patients, but many more kept track of their symptoms, questions, and emotions more informally in shorthand question lists or in free-text journals. An online system for tracking symptoms and concerns might be designed to match the less structured nature of the input, while still providing means for eliciting and displaying some of the longitudinal data in the stored information.

The responses about how the patients and caregivers report their symptoms suggest that they do not feel overwhelmed with the amount of information that they have to remember while undergoing chemotherapy. However, early on in the treatment, the patients and families may have more questions about the treatment and what to expect during the treatment. The family members and friends who are not present during the visit in particular have needs for learning more about the treatment and the cancer. This indicates that there is a need for certain information to flow from the clinic to the patients

to the family and friends. The family and friends caregivers also may need to communicate directly with the clinicians.

The patients and caregivers may communicate with the nurses for certain information in addition to the information the patients receive from the doctors. Patients may have several different clinicians with whom they share and receive different types of information. Patients also get advice and learn what to expect from other patients. There is both a desire for new patients to learn from experienced patients, as well as a desire for experienced patients to share their knowledge with the new patients. This indicates a 2-way communication desire between experienced patients and new patients, ideally with the same type of cancer, rather than just general communication among fellow patients.

Overall, the patients' and caregivers' clinical communication can involve several different types of clinicians, other patients, and the family and friends involved in the patient's care. Each of these relationships potentially could be included in and facilitated by the environment of an online cancer communication system.

### **Communication with Family and Friends**

The interview responses illustrate several types of explicit support from the patient's different relationships. The responses show that many different groups are involved in the care and support, and also that different levels of privacy are desired when sharing information with these groups and individuals. There is a need for being selective with certain information, but also a need for easily allowing open access to more general information.

Additionally, the interviews included examples of implicit support, such as the receiving or sharing prayers and the knowledge that the support network is there for the patient. The types of implicit communication might be left out of an online cancer communication system that primarily focuses on the exchange of text-based messages. Designing creative interfaces that represent the implicit communication and presence of the support network may help to enhance the supportive potential of web-based services.

The holistic aspects of the patients' and caregivers' communication suggest that a web-based system for clinical communication may need to account for the overlaps between other supportive and social interactions. The cancer patients and their informal

caregivers must balance the clinical care and communication with other aspects of their lives, and an online cancer communication system may be able to encourage a healthy balance in the patient-family communication. Likewise, it is important for the developers to be aware of how the online communication might affect the patient's other modes of communication, such as phone calls, in potentially negative ways.

### **Comparison of Media for Communication**

The results relating to a comparison of online communication and telephone communication illustrate that each medium has both advantages and disadvantages in different situations. The design of an online communication system for cancer care may be able to provide features that emphasize the positive aspects of the web-based medium while also recognizing the role of telephone-based conversations. Understanding the situations in which the telephone is preferred may help developers better understand how the online system may or may not be preferred by the patients and caregivers. Additionally, it may be possible to apply some of the basic positive aspects of the telephone conversation to the online environment. For example, certain web-based interfaces could be designed that emphasize the emotional connection between the users in a way that may parallel the feeling one gets from hearing the other person's voice on the telephone.

### **Using the Internet for Cancer Communication and Searching**

Many of the patients and caregivers have searched for cancer information on the Internet themselves or have received information from the Internet via family or friends. Several of the patients indicated that there sometimes is too much information on the Internet, and it can be hard to find information related to the patient's specific case. A few people suggested that they would appreciate information provided by Vanderbilt, because they could trust the source and they could get more targeted information related to their treatment. These responses suggest that the institution's role online might be to provide the patients with a starting point that contains original material and also recommended links to outside sources. This might be most useful at the beginning of treatment or diagnosis, which is when the patients have the most questions.

The interviews also show that many patients or their caregivers are frequent computer and Internet users. Several patients have even used relatively advanced online tools for personal journaling and supportive communication. Several of the patients and caregivers indicated that they would not be comfortable discussing the treatment with family or friends online, but several of them felt that online communication would be the preferred way to share news about the patient with certain people. Ideas suggested by the patients include a personalized Frequently Asked Questions, a video walk-through of the procedures, instant messaging with the clinic staff, and a place to find other patients who have gone through certain procedures.

### **Relationship-Centric Design Framework**

The relationship-centric design framework for online cancer communication systems was developed using the interview responses and results. The paper that describes how the interviews influenced this design framework is included in Appendix C.

## CHAPTER V

### RESULTS AND DISCUSSION – PHASE II

The Phase II results describe the interface of the prototype system. Screenshots are included for each major component of the interface.

#### Interface design and screenshots

The interface for the system consists of three main HTML frames: The top frame contains links for creating a personal profile, updating user settings, and other general user options. The side frame contains the menus for connecting with other users to send and receive messages. The middle frame displays the information content and is where all the users can write messages or perform other actions on the system.



Figure 2: All three frames with startup page

#### Relationship Portal (Side Frame)

The side frame, or “relationship portal,” is the starting point for most interactions on the system. This basic menu functions as a portal to each of the patient’s different interpersonal relationships: The clinic team, fellow patients, family and friends, as well as a private space just for the patient. The incoming and outgoing messages are organized

by each of the patient's general relationship categories. Newly received messages are visually associated with the sender's relationship with the patient; the sender's name appears in a yellow box underneath the relationship icon. In order to compose new messages, the patient first enters a certain relationship category by clicking on one of the icons. Only the people who are members of a relationship category can access the information created within that category.



Figure 3: Relationship Portal Interface

## Clinic Team

Within the patient's clinic team section, the patient has two default clinical journals. One of the journals is intended for use by the patient to record information or trends that are clinically relevant to the care team. The other journal is meant to be a place that either the patient or the clinicians can enter general information about the patient's treatment, such as details of the specific diagnosis or a personalized nutrition plan. The patient also sees a personalized list of the clinic team members who are available for the patient to contact. The patient can visit any of these clinicians' personal pages by clicking on the username.

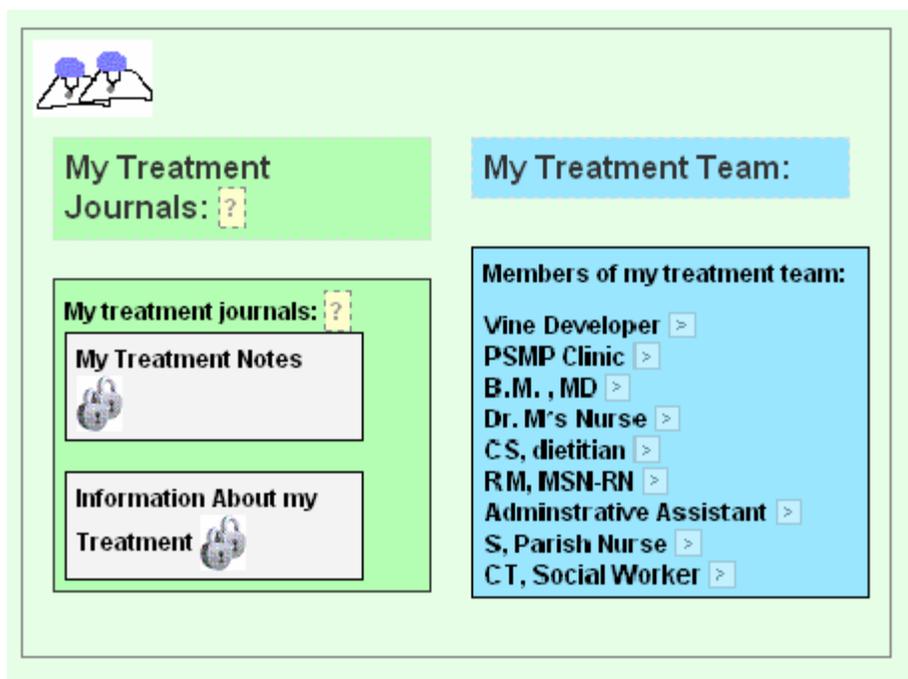
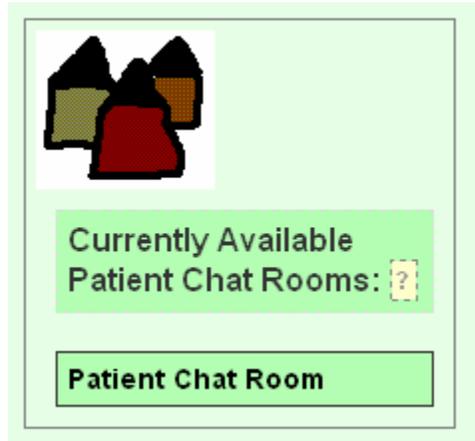


Figure 4: Communicate with the Clinic Team

## Patient Chat Rooms

In this relationship category, the patients see a list of the patient chat rooms to which they have access. Currently there is a general patient room, but other rooms specific to various diagnoses could be added in the future. The interface for each group discussion page parallels the interface for each user's personal journaling pages, and these layouts are discussed later in this chapter.



**Figure 5: Patient Chat Rooms**

### **Family and Friends**

In the family and friends section, the patient sees the list of her journals that are shared with family and friends. The “Main Journal” is automatically created, but each user can also create and define his or her own journal categories. The patient also has a link to invite family and friend users to the system by sending an invitation to their email addresses. In this same area, the patient has a contact list of their family and friends which can be arranged into user-defined groups. These groups can help the patient organize his list of contacts, and they can also be used to assign access permissions to the patient’s information and message entries. By clicking on a name in the list, the patient can send a private message to this person and can view that family member’s or friend’s own personal page. Additionally, an icon appears next to the names of the family members and friends who have visited the patient’s page within the previous 24 hours.

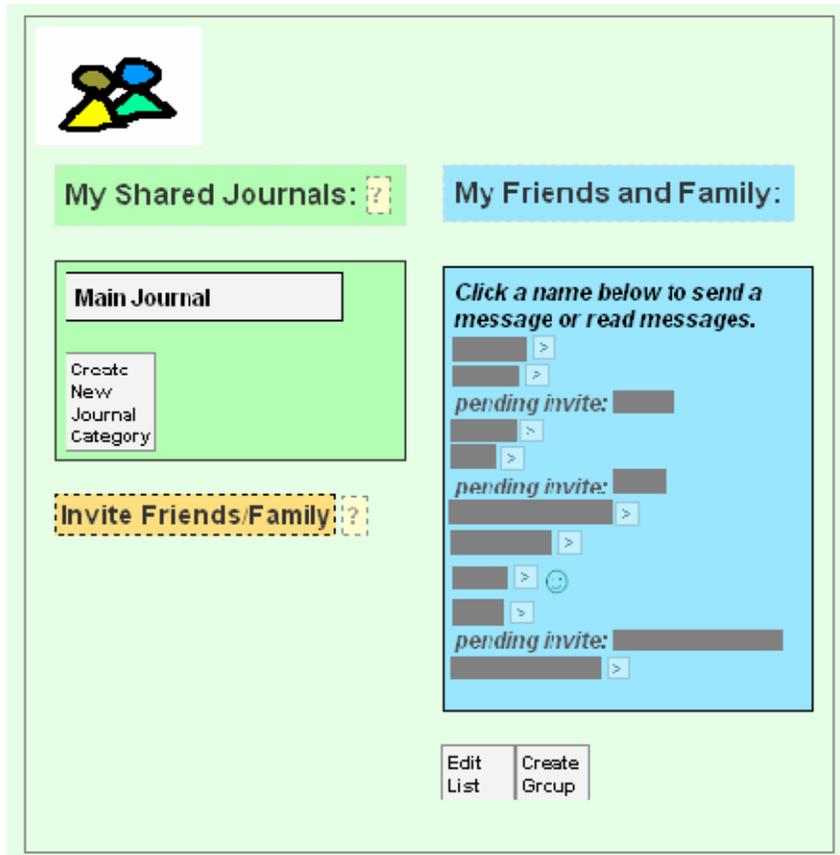


Figure 6: Family and Friends Category

## Invite Friends and Family

**Email addresses to invite (5 at a time):**

Email <input type="text"/>	Assign nickname: <input type="text"/>
Email <input type="text"/>	Assign nickname: <input type="text"/>
Email <input type="text"/>	Assign nickname: <input type="text"/>
Email <input type="text"/>	Assign nickname: <input type="text"/>
Email <input type="text"/>	Assign nickname: <input type="text"/>

**When they join, add them to group:**    
 or create a new group:

**Message to include:**

An email will be sent to the listed addresses with your message and additional information about you.

Figure 7: Invitation Form

## Private Area

Each user has a private area in which they can create journal categories that are not shared with any other users on the system. This might be used to keep a more personal, emotional diary, or it might be used to store personal reminders and notes. In this section, the user also has access to the history of all personal messages that they have received or sent to the other users on the system.

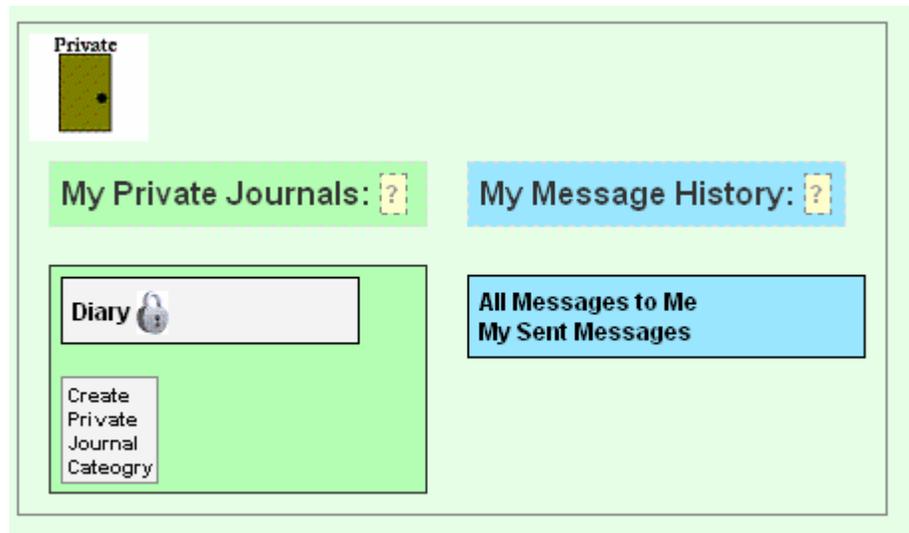


Figure 8: Private Area

## Personal Portal Pages

When a patient clicks on another user's name, she is taken to that user's main personal page. This page essentially is a portal between the patient and that user; the page includes links for the patient to interact with the user in various ways. A personal photo is featured prominently on each user's main page, along with a link to view the user's full personal profile. There also is a link for the patient to compose a new private message to the user, and the patient can also view her previous messages to and from this user.

Only the user's journal categories to which the patient has access will be listed on this page. The patient can either browse through the journal categories or search them by querying with a word or phrase. New messages from the user to the patient and new journal entries by the user will appear listed on the user's main page.

In order to make the user's page more personally relevant, the patient can assign a nickname for the user and store a personal note or reminder about the user. This portal interface also provides a link for the patient to assign another user to be a co-manager of the patient's account.

The interface for the discussion forums (i.e. "chat rooms") is equivalent to the interface for an individual user's page. Although they generally function the same way (and use the same source code) the "journal categories" are called "chat groups" instead. Also, because this page is not tied to a particular user, any user who is a member of the chat room can post messages in any of the categories.



Figure 9: Personal Portal main page



**Figure 10: Profile Page**

### **Journal Listings**

Within a user's journal category, the viewer sees the journal entries listed by author, subject, and date. The numbers of total and new responses are listed next to the subject, and the color of the subject indicates whether the viewer has viewed the entry previously. The message listing contains only one row for each original entry regardless of how many comments are added in reply to that entry. One can view the full entry and responses by clicking on the subject. If the viewer is the owner of the page, there also is a link to create a new entry within the journal category.

**John Doe (test patient)'s Pages:** Print this page

---

Journal Categories    Special Items    Assign Nickname

---

Main Journal  
[Deck](#)

Add new journal entry in Main Journal

John Doe (te...	test entry 2 (4 replies)	Tue, Jul 14
John Doe (te...	test entry	Tue, Jul 14

---

Update privacy and filter settings for category "Main Journal"...

**Figure 11: Journal Listing**

### Journal Privacy and Filter Options

The owner of a journal category can change the privacy permissions to the journal at any time. He can turn all limits off, which means that anyone who can access the owner's main page will be able to access the category. The owner can make the category private, so that only the owner can see and access the category. The owner also can limit the permissions so that only the owner's personal contacts can see the category. For the finest level of control, the owner can allow or block specific groups of contacts from accessing the category.

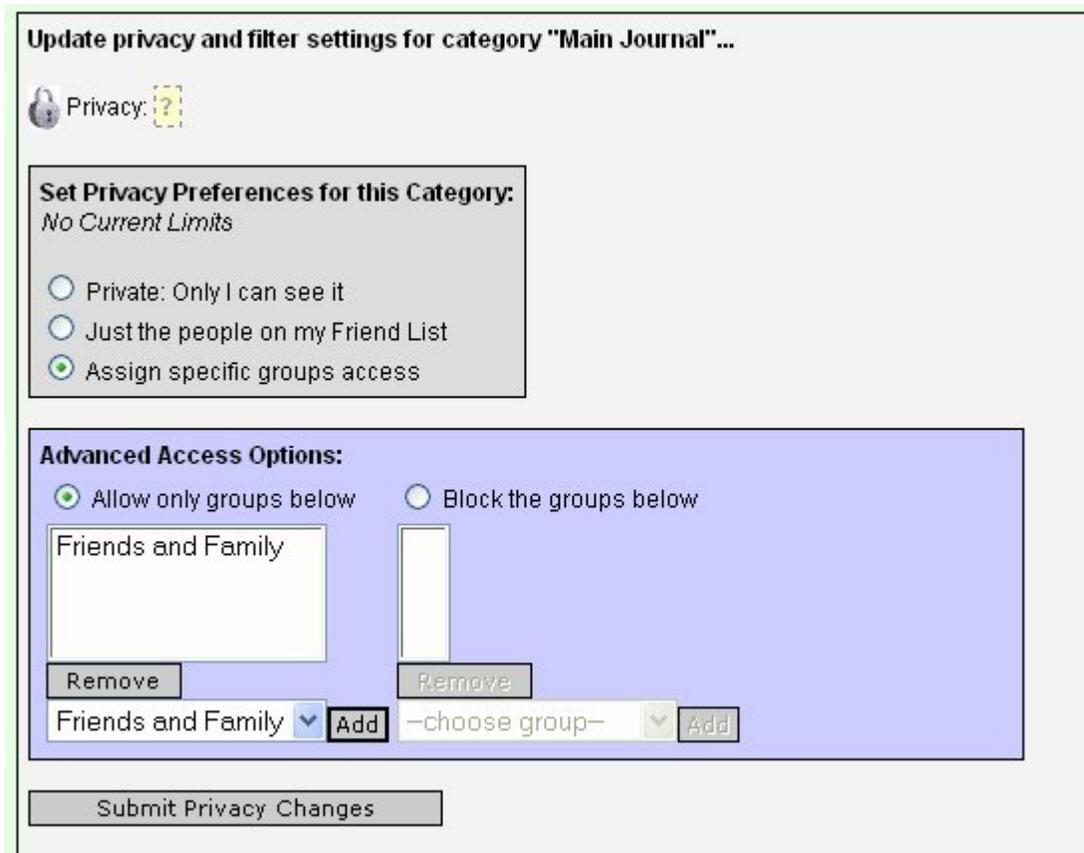


Figure 12: Journal Privacy Options

Each viewer has the option to filter a user's categories so that the viewer is only alerted about new entries in the categories in which the viewer has an interest. Within each category, the viewer can set the filter so that new message alerts are only received for the given category. Likewise, the viewer can set the filter so that new messages alerts are received for all categories *except* the given category.

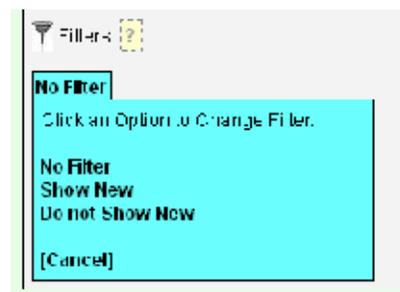


Figure 13: Journal Filter Options

## Threaded Journals and Messages

Private messages between users and general journal entries both use the same interface of threaded responses. Users can respond to the original message or entry, and they can also reply to a specific previous response. Each viewer is given the option either to reply to all viewers of the thread or privately to the author of a given message. In a private reply to a message, the response still is displayed in the context of the thread, but only the direct parent author will be able to view this branch of the thread.

The message hierarchy is displayed to the user by increasing the indentation of a child message beyond that of the parent message's indentation. New messages in a thread are indicated by the color of the subject (yellow if new; grey if old). The author of a message or reply also can edit the content at any point after it is originally created.

Additionally, the list of the users who have viewed the message thread is displayed underneath the messages. This list is only visible to the owner of the journal category.

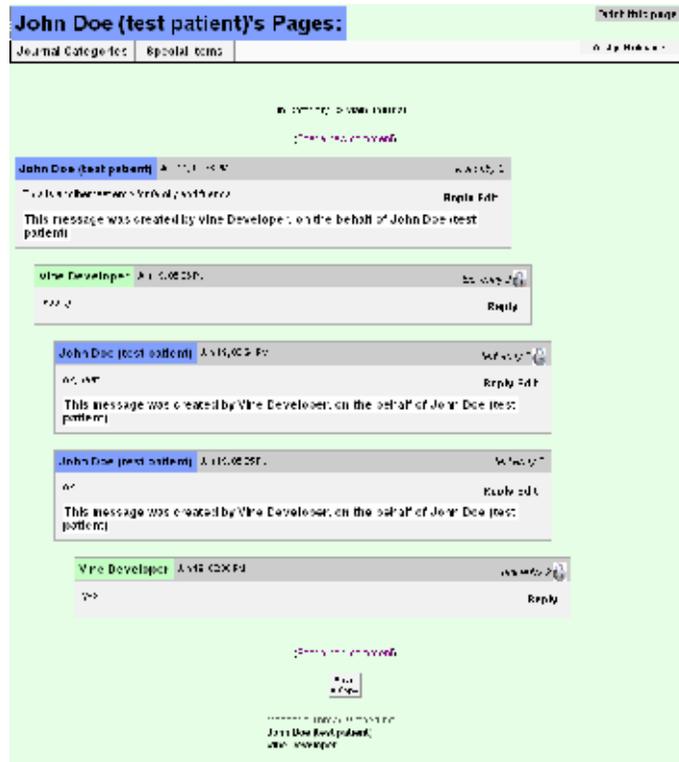


Figure 14: Threaded Messages

## Creating a New Message

The interface for creating a message currently includes an HTML text box and text area for the subject and body of the message. The author can check a box to request a reply, which adds the text “reply requested” when another user views the message. Also, the author can choose whether or not other users can post replies to the message. If the message is composed as a private message to another user, a warning is displayed above the text area to indicate that this is a directed message (as opposed to a journal entry). If it is a patient sending a message to a clinician, an additional warning is displayed to inform the patient that only non-urgent messages should be sent to the clinicians on the system.

**Barbara Murphy, MD's Pages:** [Print this page](#)

[Journal Categories](#) | [Special Items](#) | [Messaging](#) | [Assign Message](#)

### Send message to Barbara Murphy, MD:

This is a personal message directed to Barbara Murphy, MD. If you would like to write a message for multiple people to read, you can post a message in your shared journals.

If you have a medical emergency or urgent medical need, you should contact your doctor or the clinic by phone, or visit the clinic or emergency room in person. Only send messages on this system for non-urgent purposes.

**Subject:**

**Body:**

**Assign viewer permissions for this message:**

- They can read it.
- They can read and reply to it.
- Request a response.

Figure 15: Creating a new message

## Copying and Forwarding Messages

A pop up menu allows the owner of a message to copy the message into another one of that user's other journal categories. This functionality allows the user to copy a specific entry from a private journal category into a journal category that is shared with family and friends. Currently, only the original message is copied without including any of the replies to the message.

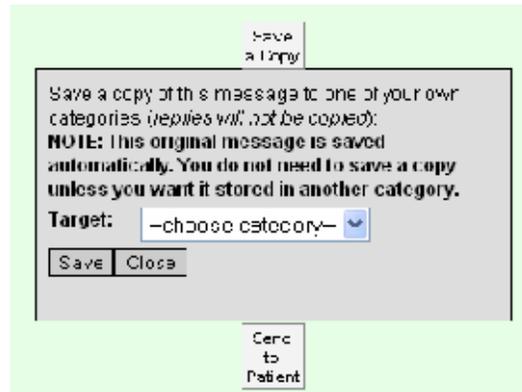


Figure 16: Save a Copy

In addition to copying a message to the user's own category, the clinicians are given the option to copy a message to one of the patient's pre-defined clinical journal categories. This allows the clinicians to store templates in their own private (or public) categories and then copy the information to an individual patient as they pertain to that patient's treatment.

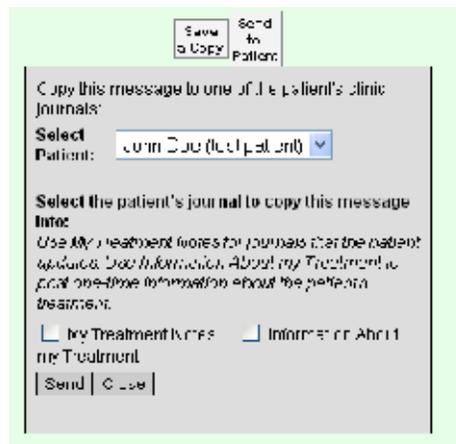


Figure 17: Send to Patient

## **Email Notification**

Users can set their personal email notification options to one of five increasing levels. On the lowest setting, no emails will be sent to the user's personal address. The next setting only sends email notifications when another person on the system initially requests access to the user's personal pages. The next setting allows a user to receive emails when someone sends a private message or posts comments on the user's own journal entries. The next setting will send an email "digest" to the user once a week if any of her contacts have posted new updates on their own pages. The highest setting will send an email notification each time there is a new message on any of the user's contacts' pages. The "digest" setting is the default setting for all users.

## **Discussion of Phase II Results**

### **Practical challenges in the system design**

Creating a system that includes clinicians, patients, families, and friends meant that the design had to address each type of user's unique role in the care. For example, the family or friends invited by the patient did not have the clinic team section in their own relationship portal menu. Also, instead of having patient-to-patient chat rooms, the family and friends menu includes the more generic "Community Chat Rooms." Likewise, instead of having a section to share journals with family and friends, the clinician users' equivalent section is labeled for sharing messages with their patients.

Unlike the user-created journals, the patients are not given the ability to change the privacy settings on their predefined clinic journals. This is meant to reduce the potential for a patient to accidentally open the clinical communication up to unintended viewers. A patient must assign another user to be a co-manager of the patient's account in order to access these protected areas. This may limit the functionality of advanced users, and if necessary it could be changed in a future iteration of the design.

### **Emphasizing the Social Spaces**

A fundamental goal of the relationship-centric framework for this design is to emphasize the social spaces and relationships between the users in ways that accurately represent the users' real world environment. In a face-to-face setting, interpersonal interactions occur within the context of the social environment. For example, the patients and caregivers visit with the doctor in the context of the clinic environment. Similarly, they may interact with their fellow church members in the context of the church functions and events. At a more basic level, a conversation between two people occurs within the social rules and roles of that specific relationship.

In the relationship portal interface, the user must consciously select one of the relationship categories before composing a new message. Similarly, new messages are presented to the user by displaying the sender's name attached to the appropriate relationship icon. Similar to a face-to-face environment, this design is intended to put the user in the mindset of interacting in the social relationship before the interaction takes place. This interface also addresses the challenges of clearly defining the boundaries between the relationships and clarifying to the user which people have access to which messages. Framing the online interactions by the social relationship may help the users feel more comfortable in writing messages that might be expressed differently in different social contexts.

### **Emphasizing the Personal Aspects of Each Relationship**

The design of each user's main page also seeks to represent the context of the face-to-face relationship before a specific interaction occurs. Each user's picture (if available) is placed prominently on the main page. This picture will be seen by the other people on the system when they visit the user's page to send a message or read new messages. This design may help the interactions on the system feel more personal and more connected to the face-to-face relationships. In the early stages of the design the profile and picture were hidden in a menu option; only the journal categories were featured on each user's main page. The personal profile and picture were made more prominent in the design because these features have the potential to add a more personal quality to the user's relationships in the online environment.

### **Personal vs. Group Spaces and Private vs. Public Spaces**

The system design provides the users with both personal space and group space in which they can express their thoughts. Personal space exists in a user's journal categories, because they are accessed by visiting that user's personal pages. Likewise, the chat groups allow a user to post messages that exist in the context of the group's page, rather than in the context of the user's own personal page. This distinction may be subtle, but providing both types of message spaces may help users express thoughts or opinions that they might not have otherwise shared. For example, users might not feel that it would be appropriate to force detailed personal updates on a group's page, but they might like to express certain emotions or news on a personal page that people can check if they are interested. On the other hand, a patient might want to post information that is of use to other patients even if it has nothing to do with the patient's own personal life. In this situation, writing to a shared group space might be more appropriate than updating information on the patient's personal page.

The design also accounts for both private and public communication spaces by providing users with private journals and journals that can be shared with other users. Even though the system primarily places emphasis on the interpersonal communication between users, each user may find uses for a private space to record thoughts and ideas without being held accountable to the other users. The private space might be used to keep a personal diary, to store self reminders about questions to ask during the next visit, or possibly for other types of self-communication. Additionally, the privacy options for the journal categories allow the users to share different information with different groups, which adds to the spectrum of private and public spaces on the system.

The ability to create private sub-threads within the context of a discussion also gives the users more flexibility in the private vs. public spaces in which they converse. Replying privately and starting a private branch of a thread could be comparable to the face-to-face interactions of pulling someone aside and talking to them apart from the group.

## **Representing presence in the design**

Although a primary goal of the design was to represent the presence and awareness of the other users on the system, it was very easy to put off the development of these interfaces when many other fundamental features seemed more pressing. The characteristics of visibility, awareness, and accountability as defined by the concept of Social Translucence exist in the design to some extent, but more work should be done to further extend this work.

The patients are made aware of recent visitors to their pages by small icons that appear next to the names in the family and friend contact list. This provides an awareness of who “stopped by” and it also makes the patient more accountable for their actions on the system. However, because the contact list is only displayed when the patient enters the family and friend relationship category, there is not much visibility of this presence in the interface. Displaying this type of presence elsewhere in the system, such as when the patient logs in, might increase the visibility and effectiveness of this interface.

Presence is also represented in the design by displaying to the patient the list of people who have read a message thread. This increases the accountability of what the patient writes in each message, and it also increases the patient’s awareness of the members of the support community who are reading each message.

## CHAPTER VI

### RESULTS AND DISCUSSION – PHASE III

#### **Introduction**

This case study describes the initial user testing of a prototype web-based system for clinical and supportive communication between cancer patients, their families and friends, and the clinic team in the cancer center. It tells the story of the first patient exploring and using the system over the course of two months. The case answers the questions of how the patient, family and friends, and the clinic team communicated on the system, how the system served its purpose effectively, in what ways was the interface confusing, and how the system can be improved. As referenced throughout this case, the name of the prototype is the “Vine online communication system.” The names of the patient and her husband are de-identified as “Jennifer” and “Tom.”

#### **Meeting the Patient and her Husband**

The developer of the Vine online communication system was introduced to Jennifer by her oncologist, Dr. Murphy, in the Vanderbilt-Ingram Cancer Center clinic. Jennifer was in her third week of chemotherapy treatment and was accompanied by her husband, Tom. The treatment schedule required them to drive to Vanderbilt for chemotherapy once a week on Thursdays.

After the patient and her husband read over the consent form, the developer described the purpose of the study and the system, and informed them that they would be the very first users to test the system. They could use the system to communicate with the clinic team, with their family and friends, and eventually with other patients once more people join the study.

The patient was enthusiastic about starting the study. Getting through the illness and treatment, she explained, requires a focus on the mind, the body, and the soul. She noted that this project would give her something to focus on and contribute to during her treatment. The patient asked if there would be a limit to the number of family and friends

she could invite to use the system; the developer said there are no limits, and she responded with a smile that her entire county back home will be on the system.

### **Background and Computer Experience**

About a year and a half ago, Jennifer and Tom moved to a city in the Southeastern United States that is about an hour and a half drive from Vanderbilt University. One of her sons and his family live there as well. Before retiring and moving, Jennifer coordinated education programs in a large county in the Midwest.

The patient and her husband have high-speed Internet access from home, and they each have a computer on which they check email before they go to bed each night. Jennifer and Tom each have their own personal email accounts, and Tom has sent email updates to their family and friends about how they are doing. Usually his emails are lighthearted and funny. Although they use email daily, Jennifer described herself as “dummy” in terms of doing anything complicated on the computer.

Many of their close friends and relatives also use the Internet or email. Tom also mentioned that one of their friends had used a web site to post health news for family and friends.

### **Registering and Initially Exploring the System**

The link to register for the Vine system was sent to the patient’s home email account the day after the patient was consented, on a Friday. That afternoon, the patient called the developer because she was having trouble registering for the system. The email program had broken the registration link onto two lines, which prevented her from easily opening the page in a web browser. The developer walked the patient and her husband through copying and pasting the URL into the web browser, and after a few tries, they were successful in accessing the secure registration page.

In reading the registration disclaimer page, the patient noted that she wouldn’t want to be cut off from the system after three months (the timeframe for the study), because she would not be through with the cancer by then. The developer informed her that she would be able to re-enroll at that point without losing her account on the system.

The patient logged into the system, and briefly explored the site while she and her husband were still on the phone with the developer. She accessed the developer's profile on the system, and jokingly said they wanted more information, like details about "a girlfriend." Jennifer asked the developer for suggestions on what to put in her private space on the system, and the developer explained that it could be used for items such as a personal journal or notes. She also was concerned about a potential conflict of interest with her radiologist brother accessing this Vanderbilt system. After she rested, she said she would start off by filling out her name and personal profile.

That weekend, both Jennifer and Tom came down with food poisoning, and they weren't in contact on the system or with the developer until the following Wednesday. They both felt too sick to try to use the computer.

## **How the patient used the system**

### **Personal Profile**

On Wednesday, Jennifer filled in the "About Me" and "My Interests" section of her personal profile, which could only be viewed by the other users on the Vine system. The user profile on Vine was based on the profile formats commonly seen in other online communities. Apart from the label for each section, there were no instructions as to what type of information the patient should include in her profile. The developer originally expected the About Me section to include a brief description of the user, and the My Interests section might be used to list a few either personal or cancer related interests.

In the About Me section, Jennifer wrote a fairly detailed background to her current situation, describing her marriages, children, and her educational and professional history. In her Interests section, she described some of her professional interests and accomplishments during her career, and that she is most proud of her four adult sons. She also added that she never smoked and drank very little, but did live with second hand smoke for the first 44 years of her life. In her Contact Information, she included her address, phone number, and email address.

## **Communicating with the Nutritionist**

### **Sending the first message**

Two days later, on a Friday afternoon, the patient sent a message to the nutritionist on Vine. The patient had previously talked with a nutritionist intern in the clinic but had not worked directly with the clinic's primary nutritionist. Jennifer introduced herself as a patient of Dr. Murphy's and described her chemotherapy and radiation treatment schedule. She had a question about a handout she received from one of the other Vanderbilt doctors on "Ideas for Increasing the Calories and Protein in your Diet." She understood that the doctors want to keep her weight up during the treatment, but the diet recommendations were very different from her normal eating habits. She finished by giving the nutritionist her current height and weight, and asked if they could meet to discuss it the next Thursday during her clinic visit.

### **Browsing the nutritionist's information**

After sending the message, the patient browsed through the nutritionist's three informational postings on high calorie recipes, nutrition plans, and constipation. The logs indicate that the patient spent a minute and a half on first posting, and about thirty seconds on the second posting. Only the time that the message is opened is recorded by the system, so it is unclear how long the patient spent on the third posting.

### **Reply from the Nutritionist**

The nutritionist was out sick on Monday, but replied to the patient's message on Tuesday morning. She told the patient to have the nurses page her once she is situated with her treatment that Thursday, and that she is very interested in seeing the handout so that she can know what the doctor's office is telling people. She told the patient that she mostly works with Dr. Murphy's patients and so she can help a lot.

The nutritionist later remarked to the developer that because she and Jennifer had already communicated before meeting in person, it was like they had already met; the rapport had already been built and it was just putting a face to the name.

### **Additional conversations with the nutritionist**

The patient and the nutritionist had another dialogue on the system a week and a half later, when Jennifer initiated a message regarding the procedure for a feeding tube. The nutritionist responded the next morning with a reassuring message about the fairly simple procedure and told Jennifer that she can explain in more detail when Jennifer is in the clinic again. Jennifer thanked her for the information, and arranged to meet with the nutritionist during the next clinic visit.

### **Communicating with Dr. Murphy**

Two weeks after Jennifer first registered on the system, the developer was working with Dr. Murphy to get feedback on the system, and Dr. Murphy used that opportunity to send an initial message to the patient to check and make sure everything was going ok with the chemotherapy. Jennifer replied the next evening, that this was one of her best weeks and she thanked Dr. Murphy for checking.

A week after first touching base online, Jennifer used the Vine system to send a clinical question to Dr. Murphy on a Saturday morning. Her head had been itching for a while and she discovered that she had a rash all over her head. She mentioned that her family doctor at home thought it might be from the pain medication, and she asked Dr. Murphy if she should see a dermatologist or if she should wait until her Thursday clinic visit. Dr. Murphy replied around 5:30pm Monday that it is probably just a simple folliculitis, and that the nurse can order a cream for it.

Two weeks after this exchange, Jennifer sent a message to Dr. Murphy regarding the timing of putting in a feeding tube. Jennifer indicated that she was asking because she needed to coordinate the clinical procedure with the schedule of an upcoming visit from a friend. Dr. Murphy replied the next morning, and said that she will make sure that the request went in to GI, and then GI will call Jennifer with the appointment. A few weeks later, Jennifer again wrote to Dr. Murphy with a concern about the feeding tube (which had been put in), and Dr. Murphy was able to send a quick reply to say that Jennifer should stop by and Dr. Murphy will take a look at it. Jennifer later mentioned to the

developer that she realizes that Dr. Murphy is a very busy person and that Dr. Murphy has been very gracious to reply right away.

### **Inviting Family and Friends – An Unexpected Design Challenge**

Around the time Jennifer completed her profile and first messaged the nutritionist, she also sent invitations to the email addresses of 12 family members and friends. Although she successfully submitted the invitation form on the system, a greater challenge for Jennifer and the developer arose in actually getting the family and friends registered to use the system.

Only three people registered and signed onto the system in the first week after the invitation emails were sent. Two people replied to the invitation email conforming that they received it, but they did not complete to the registration or log in. At Jennifer's request, the developer resent the invitations after a week. The second invitation email included more detail about the steps needed to log in and check the patient's journal updates. Within a week after this email, six more people had joined the system. A tenth person registered about three weeks later.

Jennifer later explained to the developer that several people apparently had disregarded the initial email as Spam. The invitation came from a Vanderbilt email address, as opposed to Jennifer's email address, and although her name and her welcome message were included along with a few sentences about the system, the full details about the study were included on the secure registration page for patient privacy reasons.

### **The Patient's Messages with Family and Friends**

#### **What types of messages did she post?**

Jennifer posted her first journal entry for family and friends after just over one week of using the system. In this journal entry, Jennifer described that she was starting to feel better after a rough two weeks. She described her activities, which number of the chemo treatment she was at, and described some of the support she had received from her family.

She posted a second entry ten days later. Once again, Jennifer enthusiastically wrote to express that she was having one of her best days in a long time. She described some of her procedures in the chemotherapy infusion room as a very non-threatening experience. She also talked about meeting another patient she met through church and mentioned an inspirational book that she just finished reading. She asked everyone to keep praying and to keep sending her cards and letters about her grandchildren and what is happening at work.

### **How did her friends reply?**

Eight family members and friends read her first entry and two of them wrote replies. Six people read her second entry, and two of them replied to Jennifer. One person posted a public reply to the thread, but all other responses were sent as private replies only to Jennifer. The replies to the first entry offered support, a positive attitude, and a reminder of the prayers that Jennifer was receiving. In the second entry, one person expressed confidence in the patient as a survivor and offered encouragement. Jennifer sent a private reply in return, and received one more private reply from this person. The other person to reply to the entry wrote to coordinate the schedule for taking a trip to visit Jennifer. This person explained that she is writing instead of calling because dinner is almost ready, but that she would call the next day. Jennifer replied back about possible conflicts with the clinic schedule, and that they should discuss the plans on the phone.

### **Personal Directed Messages**

In addition to replying to Jennifer's journal entry, three family members or friends initiated four separate personal message conversations with Jennifer. They let Jennifer know that that they were thinking about her, and the messages also included updates about their own personal news. Jennifer also initiated personal messages to two family members or friends to share more individualized news and to address the concerns that one of her friends had about the treatment. Two of these conversations included four messages each, two of them only had the original message and one reply, and two of them did not involve any replies.

### **Use of the Private Space**

About two weeks into using the system, Jennifer created a “Personal Journal” in her Private Space. This journal was only accessible by Jennifer, but she indicated to the developer that it was ok with her if the developer sees these entries in the database. She wrote an initial entry in this private journal, and a week and a half later she wrote a second entry. A few days after the first private entry, the developer spoke briefly with Jennifer while in the clinic. She mentioned that she tried the private journal but that it seems more “official” to type in a private journal compared to handwriting in her personal paper journal. She said that it was something that she would just have to get into the habit of doing. The developer replied that if the paper journal works better for her then that is ok; either way is fine.

### **Patient-to-Patient Chat Room**

After three weeks on the system, Jennifer posted a message in the patient chat room to introduce herself as a patient of Dr. Murphy’s and to ask if any other patients were out there so that they could get to know each other.

The developer told Jennifer that one other patient was on the system who had indicated that she might try to write to the patient chat room. But no other users checked the patient chat room, and Jennifer wrote a general hello to the group again the next week, and then a third time the week after that.

The other initial users were not actively using the system, and the developer mentioned to Jennifer that the other patients had not seen her message and that hopefully the chat room will be more active when a larger group of patients is using the system. After her third message to the group, one of the other participants on the system read the message and sent a request to connect with her on the system. But after initiating the connection, the other person did not write or reply to Jennifer’s posts.

### **Online Survey Responses**

Once a user has been on the system for at least 2 weeks, an online survey is displayed when the user logs into the system. Completion of the survey is voluntary, and it is presented to the patients and to the family and friends invited by the patients. The

survey was not fully prepared on the system until Jennifer had used the system for 4 weeks, and both Jennifer and her husband (who was invited to the system by Jennifer) completed the survey at that point.

The survey asked basic demographic questions as well as questions about the user's Internet access and usage. There were also five free response sections. These questions asked the user to explain what was easy to use, what was hard to use, what types of messages the user felt comfortable sharing on the system, how the messages on the system may be different from those on email or the telephone, and what does the person think about the general idea of a web site that includes messages between the clinic, the patient, and also with the family and friends. The full online survey responses are included in Appendix E.

### **Decrease in Usage**

A few days after Jennifer completed the survey, there was a period of a week during which she did not log into the system at all. She then logged several times over the course of a few days to send a question to Dr. Murphy and a message to the developer about a few of her family and friends still not being able to register for the system. The developer sent the invites from the system one more time to these people, but soon after that, Jennifer did not use the system for a period of about two and a half weeks. The developer was not working in the clinic during this time, and it is not known to the developer the reasons for this change in usage.

At the end of this period of inactivity, approximately 8 weeks after first signing up for the Vine system, one of the patient's friends finally sent an email to the developer to reset her password so that she could log into the system. The friend wrote to Jennifer, and this caused a message notification to be sent to Jennifer's email account. Jennifer logged in again and responded to this message. She also messaged Dr. Murphy and another family member or friend the same day. In the following days, Jennifer continued the dialogues on the system with the friend and Dr. Murphy. Jennifer had just started her daily radiation treatments (she was getting weekly chemotherapy before), and it is yet to be seen in what ways she will continue to use the system for her clinical and supportive communication.

## **How did the Clinicians use the System?**

Understanding the clinicians' use of the Vine online communication system may provide insight into what is happening "on the other end of the line" during the patient testing phase of the project.

### **Introduction of the Clinic Team**

The seven clinic team members that participated in the project were Dr. Murphy, her nurse, and five members of the Pain and Symptom Management Program (PSMP): the nutritionist, the social worker, a pain control/research nurse, the spiritual nurse, and the PSMP administrative assistant. The PSMP psychologist was not present when the developer first presented the project to the team, and she ended up not participating in the user testing. In addition to working as a medical oncologist in the clinic, Dr. Murphy is also the Director of the PSMP.

The developer met most of the team in the Pain and Symptom Management Program during the year prior to the testing phase. He initially shadowed Dr. Murphy and her nurse in the clinic, and he also attended many of the clinic team and research team meetings and events. The clinicians expressed enthusiasm about trying to use the system; particularly the nutritionist, who often works closely with Dr. Murphy's head and neck cancer patients.

### **Clinic Workflow**

Dr. Murphy has an office on an upper floor of the cancer center, but during her clinic days on Monday and Thursday she works down on the clinic floor. Her nurse generally works at one of the clinical workstations located at the center of the clinic. The PSMP team members reside together in the Patient Support Office down the hall.

The nurse typically works with the Medical Center's web-based Electronic Medical Record (EMR) system for most of the day. She also answers the phone and communicates with people in person in the clinic. The nurse also keeps her regular email open on the computer in the background, and she receives pop-up alerts for new messages. This setup potentially allows the Vine system's email notification to fit into her workflow.

Dr. Murphy typically is very busy in the clinic with a heavy load of patients each day. She uses the Electronic Medical Record to look up clinical information on workstations before, during and/or after her visits with her patients. She also has a busy schedule with research and team meetings during her off-days from the clinic.

The PSMP team members all work in the same office and are friendly when interacting with each other. Most of them also use the Electronic Medical Record on a daily basis. The clinicians are able to log into the Vine system directly from the EMR without having to re-enter their login name and password. Several of them mentioned that this makes it much easier to check Vine.

### **Creating the Clinicians' User Accounts**

When first setting up the clinician's user accounts on Vine, the developer emphasized to the team that his goal is to make this project as easy and helpful for them as possible. He explained that he had no class work over the summer and that he would be working full time on the project. The developer made sure to walk through the system in person and individually with each user. He encouraged them to send test messages to each other, to the developer, or to the test patient account on the system. He noted that the initial patients may or may not have questions for them, but they should be prepared to respond if they are contacted during the testing phase.

### **Clinician Photos and Profiles**

The Administrative Assistant provided digital photos of the Pain and Symptom Management Program team members for each of their profiles on the system. The nurse and developer each provided their own photo as well. This allowed the patients to match a face to the name when communicating with the clinic team on the system. With the developer's assistance, the clinicians also were able to reuse their biography information that already existed on the team's public web site. Several members of the team chose to make a few changes to the information when including it in their Vine personal profiles.

### **Helping the Clinicians Post Information**

Before and soon after the first patients signed up to use the system, the developer helped the nutritionist and the social worker post information from their patient handouts to their pages on Vine. The nutritionist gave the developer several written handouts to enter into the system. The nurse then checked over the online documents, made a few changes from the originals, and added them to her page for the patients to access. The social worker wrote up a few paragraphs on transportation, lodging, and related services and posted them to her page with the in-person guidance of the developer.

### **Feedback from the Clinicians**

Throughout the testing phase, the developer periodically would stop by the Patient Support Office during the week to chat with the team and to check if they had any questions or issues with the system. Dr. Murphy had several suggestions about the wording of the components in the design and about the layout of the interface. The nutritionist and others also made comments about what might make the system easier to use from their perspective. The nutritionist mentioned that the ability to log into Vine through the Electronic Medical Record made the system easier to work into her workflow.

### **Discussion of the Design and Initial Usage**

#### **How was the system used as intended?**

No specific assignments were given to the patient to use the system in a specific order or manner. Suggestions were offered when the patient asked the developer about the meaning of a specific section or item, but most aspects of the system were left open for her to use as she desired.

#### **Use and overlap of the different relationships categories**

The patient made an effort to use all of the different relationship components of the system by communicating with the clinic team, posting messages to the patient chat room, writing updates for family and friends, as well as writing in a private journal. The

lack of other active users prevented much use of the patient-to-patient features, and the patient was more comfortable writing her private thoughts in a handwritten journal. But still, she did at least make an initial attempt to use these aspects of the system.

Additionally, the patient's messages provided several examples of situations in which the clinical and social communication seemed to complement each other as two components of a single application. For example, early on when Jennifer received initial messages from Dr. Murphy and from one of her invited family or friends, she responded to them both during the same session, letting each one know that she had a good week. Similarly, when Jennifer sent Dr. Murphy a question about a rash one morning, she also wrote to one of her family and friends that evening about the rash and that she had messaged the doctor about it. Another time, she wrote a reply to the nutritionist, then posted to the patient-to-patient chat room, and then wrote her second family and friend update all within 25 minutes of each other.

When Jennifer had not logged in for two and half weeks and her friend sent a message, Jennifer not only logged in to respond to her friend, but she also messaged Dr. Murphy about a concern brought up by the friend regarding the feeding tube. Although it cannot be known fully from just the message logs, the friend's message appeared to prompt the communication between Jennifer and Dr. Murphy on the system. Additionally, after writing back to the first friend and to Dr. Murphy, Jennifer also initiated a message to another family member or friend who had expressed concerns to Tom via email. Jennifer let this person know that the doctors say she is doing just fine, and she gave more details about the treatment and how it is affecting her.

### **Use of both general journal updates and private personal messages**

Jennifer utilized both her public journal as well as private messages when communicating on the system. She posted two updates for all of her family and friends, but she also sent and received separate personal messages with several of these people. Also, except for the very first response to her first journal entry, all of her family members and friends sent replies to the thread privately instead of writing a public comment. These replies generally were very personal in content and tone, and the ability to create private sub-threads under the patient's original message may have contributed to

personal qualities of these responses. Jennifer's public journal entries sparked multiple individual conversations, but all of these supportive messages still are organized together under the original journal postings. If Jennifer revisits a journal thread at a later date, she will be able to reread her entry along with all of the replies and the ensuing private discussions.

The patient mentioned to the developer that displaying new messages in the context of the thread history might be good because with chemo it is easy for her to forget things. For this reason, giving the family and friends the ability to reply privately but still within the context of the previous messages may help patients who have trouble with memory during chemotherapy.

### **Mixture of online, face-to-face, phone, and email**

The online communication system was intended to be used as an additional way for the patient to communicate with the people with whom she already has a face-to-face, phone-based, or email-based relationship. During the testing phase the communication between the patient, the clinicians, and the family and friends was spread across several modes of communication. For example, many of the clinical questions were initiated online but were not fully answered online. Instead, the clinicians and the patient arranged to discuss the issue during the next clinic visit. Likewise, the patient followed up online with the nutritionist regarding the material that they had discussed in person in the clinic.

Likewise, Jennifer indicated in the online survey that "Not all of my friends e-mail me through this system, they just use the regular e-mail." Online messaging on Vine and messaging on regular email therefore do not have to replace each other, but they both can add to the total supportive communication. Online messages with family and friends on Vine also might result in more supportive communication on the telephone. The friend who just recently signed on to the system indicated that she doesn't know when it is okay to call Jennifer at home, as she does not want to disturb her. As part of her reply, Jennifer said not to be afraid to call, and she indicated the best days to call her at home.

## **What parts of the design were not fully utilized?**

### **Clinical Notes and Journals**

This patient did not use her clinical journals to write notes or concerns related to her treatment. She did save some of the personal messages from the clinicians to these journals, but this may have been due to confusion over whether the personal messages are automatically saved or not. Also, the clinicians did not create any personalized care plans or information about the patient's specific case in these journals. The clinicians did post general information to their own pages, but only with the help of the developer. Dr. Murphy had planned to post several items to her page, but her busy schedule prevented her from being able to do this.

### **Patient-to-Patient Communication**

Although five patients were recruited for this study, one patient withdrew from the study, another patient was unable to participate due to illness, and Jennifer was the only one of the three registered patients to actively use the system. Jennifer indicated in the online survey that she is looking forward to meeting other patients, but more active users would be required to fully utilize the patient chat communities on the system.

### **No additional journals, user groups, or co-managers were created**

Jennifer posted three updates for family and friends in her Main Journal, but she did not create a second journal category to share information with a subset of her support network. She did not organize her contact list into specific subgroups, and so all members on her list had access to the same information. Jennifer did indicate a few times early on that she would like her radiologist son to be able to communicate with the doctors, but she never did make this assignment on the system.

## **What feature was most desired by the patient? Spell Check!**

In the online survey, spell check is what Jennifer said was most needed on the system. She had mentioned that she would like spell check when first introduced to the project, and she asked about it several times during the study. A plan was already in place

to add a spell check library to the clinical web server (requested by doctors), but the developer was not in a position to add it himself. The developer frequently checked with the manager of the clinical servers to ask about the progress of implementing this functionality, and the developer passed this information on to Jennifer.

The extent to which the lack of spell check affects the patient's use of a system may not always be obvious to the developers. During the first week of use when the patient asked the developer a question about submitting her personal profile, she mentioned that she read over her profile four times to check for spelling errors. This time-consuming task is not recorded in any usage logs, and this might also be occurring with other users on the system. If questions about spell checking are not explicitly asked in an evaluation of a system, situations like this might remain hidden from the development team.

### **What aspects of the design did the users find confusing?**

Although the patient was able to use the system for her supportive and clinical communication, several aspects of the interface still were confusing.

#### **It's not quite like standard email**

The Vine system allows a user to send directed personal messages to the other users, such as when Jennifer asked a question to a member of the clinic team. The system also gives the users their own online journals in which they can post messages for their family, friends, or groups to read. This was used by Jennifer to post her general updates for family and friends.

With the default notification settings, an email alert is sent to the recipient's regular email when the patient sends a personal message on the system. However, when the patient updates her Main Journal with a general posting, an email is not automatically sent to the family and friends. Instead, the users will receive a weekly "digest" email if there are new journal entries on the system for them to read. This setting was intended to prevent the system from sending too many unsolicited emails, such as if a user were to update her journal with thoughts and comments multiple times a day. There was no tutorial or clear explanation for how a journal update differs from a traditional mass email

that would be pushed to each recipient's inbox. Jennifer was confused and asked, "It doesn't alert them on their e-mail that they have a message from me?" Perhaps this confusion was compounded by the fact that Jennifer received email alerts each time the developer or the clinicians sent her a directed message or reply on the system.

A similar confusion occurred with the patient's profile. After she edited her personal profile, Jennifer messaged the developer to ask if he had sent her profile to anyone yet, or if she needed to send it to her friends and family. Again, there was confusion over which information is published for people to access at their leisure and which information is pushed out to others.

### **When do you need to save a message?**

Another confusing aspect about the design was the option to save a copy of a message to a journal category. At the bottom of each message or journal thread there was a button labeled "Save Message", which opened a menu to copy the message to another category. This feature was intended to allow users to share personal messages or private journals by copying them individually into a public category. However, the presence and phrasing of this button might make it seem as if incoming and outgoing messages would not be stored in the system if they were not saved to a journal category. Both Jennifer and the nutritionist save copies of personal messages to one of the clinical categories just to make sure they were saved somewhere. This added more confusion, because it then appeared to the clinicians that Jennifer had a new entry in her clinical journal (when it was really a saved personal message).

### **Confusion over who can access which sections and messages?**

Although the system design divided the interface into separate clinical, patient-to-patient, family/friend, and private sections, it still was not clear to the patient who had access to which messages. Jennifer mentioned in the online survey that, "I have used my private space the least. I'm still not sure who can have access to it. I write in a book journal and feel more private." Also, when first posting to in her Main Journal, she messaged the developer to double check that the entry did actually go to her family and friends. When the patient posts a new journal entry, there is no explicit confirmation or

reminder about which specific users can access the message or who would receive email notifications. The lack of feedback in the interface was partially supplemented by giving the patient direct access to confirm with the developer what she sent.

### **Journal Listings and Thread Interfaces**

From observing the usage logs, the developer noticed that some of the family and friends would access the patient's page and/or profile without viewing her journal entries. If there wasn't a new message displayed on Jennifer's main page, the family and friends may not have immediately realized that they must click on the Main Journal box to view the previous entries.

The patient also expressed confusion over the button that said "Reply to Thread"; she asked the developer "what is a thread?" The patient had always used the button labeled "Private Reply to [Username]" when replying a message. In the online survey, Jennifer wrote that "Some of the terminology was a little different. But, [the developer] and I worked through most of it."

### **Trouble Registering and Logging In**

One of the biggest challenges was getting the family and friends registered and logged in on the system. The patient mentioned that at least a few people thought that the invitation email was Spam and therefore didn't follow the link. She also said at one point that she thinks that the people don't realize that they need to sign on to read her messages. The patient's husband had trouble logging in when he forgot his password, and another friend could not log in for several weeks until she emailed the developer and had her password reset. Jennifer suggested a more standard introduction in the invitation email so that the family and friends know that it is legitimate.

The clinicians also had trouble logging into the system. The system was expecting their clinical workstation userID and password, but they sometimes forgot which password to use. In one case, the patient sent Dr. Murphy a message and Dr. Murphy got the email notification and clicked the link to login, but she forgot that she needed to use her clinical password. She was busy and had fifteen other emails to read through, so she didn't waste time trying to figure it out. The clinicians did not have the same trouble

when they accessed Vine directly from the Electronic Medical Record, because they were not required to login again.

### **What changes were made based on the feedback and initial use?**

#### **Email notifications**

At first, the default email notification setting only would send emails for private messages sent directly to the user. But because of Jennifer's expectation that her family and friends would be notified of her new entries in her journal, the weekly digest option was created and set as the default. An email notification is sent once a week but only if there are new messages waiting for the user to check. In this change, the developer sought to make the system more accessible while still preventing the system from sending an overwhelming number of messages to the entire contact list.

#### **Simplifying the steps to finding the patient's updates**

Two changes were made during the testing phase to make it easier for the family and friends to find and read the patient's journal updates. Instructions were added to the initial invitation email to inform the new users of how to find the patient's journal updates once they log into the system. Initially, when a family member first registered for Vine, they would need to go to their own "Friends and Family" section to find the patient's name. After clicking on her name, they would open her Main Journal to see the listing of entries, and then click on an entry to read it and reply. After about two weeks, the developer changed the startup page so that when the family and friends log into the system they would immediately be taken to Jennifer's main page. They still need to click on her Main Journal to see her updates, but this change reduced several steps along the way. Starting with a focus on the patient also seemed to fit more naturally with the family and friends roles on the system.

#### **Icons and Phrasing of labels**

A few changes were made to the wording of some features based on suggestions from the patient and Dr. Murphy. For example, the patient suggested that the "Update

Profile” button for saving the personal profile should be labeled, “Submit Profile.” Dr. Murphy also suggested that including icons for the links in the outermost menu would make the interface easier to navigate.

### **Next steps for improving the design**

#### **Simplify and Clarify**

The Vine system allows patients to define custom groups of family and friends, create multiple journals, and create custom privacy settings for each group. While these features may still be important to include, the system also should be able to satisfy the needs of those users who do not utilize these features. The initial interface for the system might be kept more basic, while still allowing users to turn on the advanced features when desired. For example, if the patient only uses the Main Journal, perhaps the entry listing could be displayed directly on the patient’s main page.

Additionally, more clarification is needed about who can see which messages and about the difference between directed messages and journal entries. Perhaps a simple confirmation when a message is created could list the individuals or groups who currently have access to the message and whether or not an email notification was sent to each person. Dr. Murphy also indicated that there should be a much clearer distinction between messages and journal entries. She suggested including distinct links on the main side menu for both messages and journals across all relationship categories.

#### **More emphasis on presence**

The developer intended to emphasize the presence of the online supportive community more prominently in the system. Currently, the startup page for the patient is undeveloped, and this could be an excellent piece of screen real estate to include creative interfaces that indicate to the patient the presence and support of the family and friends. Especially with the challenges that Jennifer encountered when inviting the family and friends to access the system, this functionality may be especially helpful when the patient first starts using the system.

### **Integration with the Clinic Workflow**

The current system does not allow Dr. Murphy to forward her new message notifications to her nurse's email address. This functionality might be important at times when Dr. Murphy is too busy to check her email for new messages. Along these lines, a more complete system could be integrated with the Electronic Medical Record, which already is a central component of the clinic's workflow.

### **Logistical Needs**

Finally, there are several logistical areas in which there is room for improvement. An easier means for users to reset their password without emailing the developer could help reduce the confusion over logging into the system. Also, spell check would be a very welcome addition to the system.

### **Ethical Challenges - Protecting the Patient vs. Not Interfering with the System**

Because Jennifer was the first actual patient to use the system, the developer had an ethical concern of preventing her from accidentally sharing of private information. However, he also did not want to interfere too much with the patient's self-directed use of the system. The developer had to recognize his own personal biases about what information is considered "sensitive." For example, when the patient included details about previous marriages in her profile, the developer initially was concerned that the patient might not understand the doctors and the family and friends can read her profile. However, when the patient indicated that her adult children are what she is most proud of in life, those details become very relevant to her personal story, and potentially even to a decision she might make at some point regarding her care. The developer did not interfere in this situation, because simply asking if the patient really intended to share a message would automatically be casting judgment on the content of the communication. Still, these were very real concerns for the developer in monitoring the system.

Similarly, even though the patient was instructed not to use the system for emergent concerns, the developer did not always know if the patient's message actually was an emergent concern. He did not want the patient to have a lower standard of care in case an important message to Dr. Murphy was left unchecked during the busy clinic days. The first time the patient sent a clinical question to Dr. Murphy about a rash, the developer did mention to Dr. Murphy that there was a clinical question waiting for her on the system.

### **Summary**

Jennifer was enthusiastic about participating in the project, and she was very helpful in providing feedback to the developer whenever she was confused about part of the system. It is clear that much more work needs to be done to simplify and streamline the interface, and certain specific functions, such as Spell Check, should be added. However, despite the slightly clunky feel of the prototype system, Jennifer enjoyed checking for messages on the system and she was able to use the system to supplement both her clinical and her supportive communication. She told the developer that it has been most useful to be able to communicate with Dr. Murphy on the system. Likewise, Dr. Murphy mentioned that it took her a little while to overcome the initial hurdle of using the system, but when she was able to quickly send a message to the patient to solve a real problem, she began to realize the potential of this type of communication. Jennifer's initial use of the Vine system suggests that combining the clinical and supportive components of cancer communication into a single online interface can introduce unique types of interactions that might not be possible through two isolated messaging systems.

## CHAPTER VII

### CONCLUSIONS

The research hypothesis for this study was that an informatics system can effectively support the communication needs of cancer patients and their informal caregivers. The research was conducted in three phases:

The first phase of the research illustrated the clinical and supportive communication patterns and desires of cancer patients and their families through the qualitative analysis of sixteen semi-structured interviews. The interviews provided examples of several aspects of communication that could be applied to the design of an online cancer communication system. For example, a type of implicit communication and support occurs when patients know that family and friends are thinking about them and that those people available to help if needed. The presence of the patient's support network could be represented in an online communication system through specific interfaces in the design. The interviews also provided examples of ways in which patients and caregivers use the Internet and email for cancer communication and how the clinical and supportive communication can overlap in certain holistic situations.

In the second phase of the research, a prototype system for clinical and supportive communication was developed using a relationship-centric design framework. The high-level principles elicited from the interview results guided the design of the prototype. The design included interfaces that emphasize the different interpersonal relationships in which the users can share information and supportive messages.

The third and final phase of the research involved initial testing of the prototype system with patients, their family and friends, and their clinicians. The purpose of this phase was to determine the usability and feasibility of the prototype in order to iteratively redesign and improve the system. The system was evaluated using a case study methodology of a single patient and her relationships. The user feedback on the prototype system showed that the patient-caregiver integrated network may be a viable option for online cancer communication, but there is much room for improvement in the interface design.

### **Limitations of this Study**

Several limitations to this study should be noted. In the analysis of the interviews, no interrater agreement was utilized to assign concept labels to the responses. The interviews, transcription, and analysis were all conducted solely by the author, which may introduce a bias to the Phase I interview results. The interview subjects were all patients (and their families) who were receiving treatment from oncologists in the same cancer clinic. The results from these subjects might not generalize to other populations.

In the prototype design, the final interface is just one possible design that embodies the relationship-centric design framework. Many other interfaces could be designed by starting with the same set of high-level design goals. Due to time limitations and maintaining simplicity in the initial design, many of the suggestions offered by the patients and caregivers in the interviews were not included in the current interface. Additionally, the relationship-centric framework has not been fully studied as to how it should or shouldn't be applied to certain clinical and supportive communication systems. A more formal analysis of this framework is has yet to be completed.

In the testing phase of the study, only one patient fully used the system and provided feedback to the developer, and this single case study may not generalize to the design views and needs of other patients. The case study does illustrate important aspects of the system in a real-world setting, but this is not necessarily the only possible usage scenario. Also, the system was only used by a subset of the clinicians in the cancer clinic, and so the initial usage may not reflect how the system would be used in a full scale institution-wide implementation.

### **Future Work**

More fundamental social and psychological science analysis should be conducted to understand how the patient and family's social and clinical roles in face-to-face relationships affect and are influenced by an online cancer communication system. Formal studies of the social and clinical communication spaces across several communication media could provide more insight into the potential benefits and risks of including these different relationships in an online system design.

Several themes from the interviews might be applicable to online communication systems in other medical domains that often involve clinical and supportive communication with the patient's family and friends. The relationship-centric design framework also might be useful in developing or evaluating online communication in other medical or even general consumer applications. Additionally, the lessons learned from the user testing phase may provide insight into some of the challenges involved in designing and testing other types of systems for patients and their support networks.

In relation to the bigger picture of consumer health informatics, the patient's supportive and clinical communication may have a valid place as a component of a life-long Personal Health Record owned and controlled by the patient. Including the communication between the patient, the clinicians, and the family and friends may help patients document important aspects of their medical and personal story. If clinical communication is an important part of the patient's treatment, then the documentation of messages with the patient may be a useful component of the patient's personal, longitudinal health record. Research could be conducted to determine how to appropriately include these discussions in a Personal Health Record while still respecting the confidentiality and ownership rights of all involved parties.

Several specific questions about clinical and supportive communication could be studied in larger controlled trials using a more complete system. For example, how do new patients use the communication tools differently as compared to experienced patients? How does the use of the system affect the patients' and the caregivers' clinical outcomes and quality of life? How would usage and outcomes change if the different components of the system were included or excluded for different groups of users? These questions and others could be the basis for several future studies.

## **Conclusion**

This work only represents one step towards better understanding the multifaceted roles and relationships of clinicians, patients, and family and friends in online cancer communication systems. As more communication occurs through electronic media in our societies, understanding the social, clinical, and practical challenges of integrating these

relationships will be a critical step in designing effective paradigms for health-related online communication.

## APPENDIX A

### SURVEY FORMS

Dear Participant,

I am a graduate student in the Department of Biomedical Informatics at Vanderbilt University, working with Dr. Nancy Lorenzi. The goal of this research is to understand how patients and their family and friends communicate about cancer, cancer symptoms, and cancer-related pain. We wish to investigate the ways that you keep track of symptoms and how you talk to doctors about your questions and concerns. We also wish to investigate the ways that you talk to your family and friends about cancer and how you receive support from them.

Your input will help us design an Internet-based tool to assist patients and informal caregivers with communicating about pain, symptoms, and other issues related to cancer.

Your responses will only be used for the purpose of this research. All individual responses are completely confidential. Any illustrative quotes or data from individual responses will be reported in such a way that it will be impossible to determine the identity of individual subjects. Completing the survey and interview is entirely voluntary, and by doing so you consent to having the survey and interview responses used in the study.

The study consists of a survey and an interview:

1. **The survey** will take about **15 minutes** and will be completed by each person individually. You will be asked general background questions, questions about communicating with doctors, and questions about communicating with family, friends, and acquaintances. You also will be asked about your interest in using the Internet to communicate about cancer-related information and support.
2. **The interview** will be held as a group discussion in a private room with the primary research investigator, the patient, and the family or friends who are present for the visit. The interview will take about **30 minutes**. It will cover the same topics as the survey, and will allow you to express your communication needs and experiences in your own words.

The primary investigator will record audio and written notes during the interview, and only the primary investigator and his Faculty Advisor will have access to these recordings. No other persons will have access to listen to the recordings or identify the speakers. Any illustrative quotes from the interview will be reported in such a way that it will be impossible to determine the identity of individual subjects.

You may refuse to answer any question at any time, and, again, all individual responses will be entirely confidential and anonymous.

If you should have any questions about this research study, please feel free to contact Jacob Weiss at 615-936-1773, or my Faculty Advisor, Dr. Nancy Lorenzi at 615-936-1423.

For additional information about giving consent or your rights as a participant in this study, please feel free to contact the Vanderbilt University Institutional Review Board Office at (615) 322-2918 or toll free at (866) 224-8273.

Thank you for your participation in this study,  
Jacob Weiss  
Department of Biomedical Informatics  
Vanderbilt University

## Caregiver Phrasing:

### Family Geography and Demographics

1. Describe your relation to the patient? <input type="checkbox"/> Partner/Spouse <input type="checkbox"/> Immediate Family <input type="checkbox"/> Relative <input type="checkbox"/> Friend <input type="checkbox"/> Other: _____
2. Are you the primary family/friend caregiver? <input type="checkbox"/> Yes <input type="checkbox"/> No
3. Do you live in the same home as the patient? <input type="checkbox"/> Yes <input type="checkbox"/> No
4. How many of your close friends or relatives live in the same town or city as you? <input type="checkbox"/> None <input type="checkbox"/> A few of them <input type="checkbox"/> Most of them <input type="checkbox"/> All of them
5. How long does it take you to travel to the Vanderbilt-Ingram Cancer Center? _____ hours, _____ minutes
6. How often does the patient come to the Vanderbilt-Ingram Cancer Center for treatment? <input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> Monthly <input type="checkbox"/> Other: _____
7. What is your age (in years): _____
8. What is your gender? <input type="checkbox"/> Male <input type="checkbox"/> Female
9. Describe your racial group: <input type="checkbox"/> White (Non Hispanic) <input type="checkbox"/> Hispanic or Latin Origin <input type="checkbox"/> African American <input type="checkbox"/> Bi-racial: _____ <input type="checkbox"/> Asian/Pacific Islander <input type="checkbox"/> Other: _____

### Internet and Telephone

1. In the past week, I used... (check all that apply) <input type="checkbox"/> Telephone <input type="checkbox"/> Email <input type="checkbox"/> Web pages <input type="checkbox"/> Instant Messaging (IM) <input type="checkbox"/> "Text Messaging" on a cell phone
2. Do you carry a cell phone when you leave home? <input type="checkbox"/> Yes <input type="checkbox"/> No
3. Do you have Internet access at work? <input type="checkbox"/> Yes <input type="checkbox"/> No
4. Do you have Internet access at home? <input type="checkbox"/> Yes <input type="checkbox"/> No → If 'Yes,' is it: <input type="checkbox"/> dial-up or <input type="checkbox"/> broadband (cable/dsl) or <input type="checkbox"/> don't know
5. How many of your close friends and relatives use the Internet or email? <input type="checkbox"/> 0 <input type="checkbox"/> 1-2 <input type="checkbox"/> 3-4 <input type="checkbox"/> 5 or more <input type="checkbox"/> Don't know

## Pain and Symptom Management / Asking Doctors Questions

1. **How do you help the patient remember questions or concerns to discuss with the doctor during the visit** *(check all that apply)*
  - I write a list of questions on paper
  - I remember the questions, without writing anything down
  - This question does not apply to my role in the patient's care
  - Other, please explain:
  
2. **How do you help the patient remember what the doctor tells the patient during the visit** *(check all that apply)*
  - I take notes during the visit
  - I remember without writing anything down
  - I write up notes after I get home
  - This question does not apply to my role in the patient's care
  - Other, please explain:
  
3. **How do you currently help keep track of the patient's pain levels at home** *(check all that apply)*
  - I write notes in a journal or chart:  **Hourly**    **Daily**    **Weekly** *(check how often)*
  - I only write a note when there is a significant change
  - I just make a mental note
  - This question does not apply to my role in the patient's care
  - Other, please explain:
  
4. **How do you currently help keep track of the patient's other symptoms at home** *(check all that apply)*
  - I write notes in a journal or chart:  **Hourly**    **Daily**    **Weekly** *(check how often)*
  - I only write a note when there is a significant change
  - I just make a mental note
  - This question does not apply to my role in the patient's care
  - Other, please explain:

Circle a number for each of the following statements:	Never → Frequently
5. During the visit, I sometimes forget to ask the doctor certain questions about the patient	1 2 3 4 5
6. During the visit, I sometimes am embarrassed to ask the doctor certain questions about the patient	1 2 3 4 5
7. After the visit, I sometimes forget the instructions or information that the doctor tells the patient	1 2 3 4 5
8. I need more information about managing...	
a. the patient's pain	1 2 3 4 5
b. the patient's other symptoms	1 2 3 4 5
c. side effects from the chemotherapy or other medicines	1 2 3 4 5
<b>Strongly Disagree → Strongly Agree</b>	
9. If I could ask questions in writing, I would ask the doctors more sensitive or embarrassing questions	1 2 3 4 5
10. I hope the doctor would bring up the patient's or my own ...	
a. <i>emotional</i> concerns	1 2 3 4 5
b. <i>practical</i> concerns	1 2 3 4 5
11. I believe the patient or caregiver should bring up...	
a. <i>emotional</i> concerns	1 2 3 4 5
b. <i>practical</i> concerns	1 2 3 4 5

**READ THESE DEFINITIONS BEFORE CONTINUING:**

**In the next section, you will be asked about how you communicate with Family, Friends, and Acquaintances/Co-workers:**

- **“Family”** means your partner/spouse, and your immediate families and relatives.
- **“Friend”** means someone with whom you choose to share a close bond. This is someone outside of your family in whom you can confide and discuss personal issues and concerns.
- **“Acquaintance/Co-worker”** means someone with whom you socialize, keep in touch, or see on a regular basis, but with whom you do not share a close personal bond. Your casual friends, neighbors, and other members of the community would fall into this category.

## Talking about cancer and care needs with family, friends, and others

Check only the answers that apply to you:

**1. I give general updates about the patient's activities to the patient's or my own:**

<b>Family:</b>	<b>Friends:</b>	<b>Acquaintances/C o-workers:</b>
<input type="checkbox"/> In person	<input type="checkbox"/> In person	<input type="checkbox"/> In person
<input type="checkbox"/> On the Telephone	<input type="checkbox"/> On the Telephone	<input type="checkbox"/> On the
<input type="checkbox"/> Via Email	<input type="checkbox"/> Via Email	Telephone
<input type="checkbox"/> Written Letters	<input type="checkbox"/> Written Letters	<input type="checkbox"/> Via Email
		<input type="checkbox"/> Written Letters

Other (please explain): \_\_\_\_\_  I ask someone else to handle this for me

**2. I discuss specific details of the patient's treatment with the patient's or my own:**

<b>Family:</b>	<b>Friends:</b>	<b>Acquaintances/C o-workers:</b>
<input type="checkbox"/> In person	<input type="checkbox"/> In person	<input type="checkbox"/> In person
<input type="checkbox"/> On the Telephone	<input type="checkbox"/> On the Telephone	<input type="checkbox"/> On the
<input type="checkbox"/> Via Email	<input type="checkbox"/> Via Email	Telephone
<input type="checkbox"/> Written Letters	<input type="checkbox"/> Written Letters	<input type="checkbox"/> Via Email
		<input type="checkbox"/> Written Letters

Other (please explain): \_\_\_\_\_  I ask someone else to handle this for me

**3. I have asked for practical help in caring for the patient, or I received offers for help from the patient's or my own:**

<b>Family:</b>	<b>Friends:</b>	<b>Acquaintances/C o-workers:</b>
<input type="checkbox"/> In person	<input type="checkbox"/> In person	<input type="checkbox"/> In person
<input type="checkbox"/> On the Telephone	<input type="checkbox"/> On the Telephone	<input type="checkbox"/> On the
<input type="checkbox"/> Via Email	<input type="checkbox"/> Via Email	Telephone
<input type="checkbox"/> Written Letters	<input type="checkbox"/> Written Letters	<input type="checkbox"/> Via Email
		<input type="checkbox"/> Written Letters

Other (please explain): \_\_\_\_\_

**4. I have given or received information about cancer, treatments, or caregiving from the patient's or my own:**

<b>Family:</b>	<b>Friends:</b>	<b>Acquaintance s/Co-workers:</b>
<input type="checkbox"/> In person	<input type="checkbox"/> In person	<input type="checkbox"/> In person
<input type="checkbox"/> On the Telephone	<input type="checkbox"/> On the Telephone	<input type="checkbox"/> On the
<input type="checkbox"/> Via Email	<input type="checkbox"/> Via Email	Telephone
<input type="checkbox"/> Written Letters	<input type="checkbox"/> Written Letters	<input type="checkbox"/> Via Email
		<input type="checkbox"/> Written Letters

Other (please explain): \_\_\_\_\_

**5. I have discussed my own emotions about the patient's cancer with the patient's or my own:**

<b>Family:</b>	<b>Friends:</b>	<b>Acquaintances/C o-workers:</b>
<input type="checkbox"/> In person	<input type="checkbox"/> In person	<input type="checkbox"/> In person
<input type="checkbox"/> On the Telephone	<input type="checkbox"/> On the Telephone	<input type="checkbox"/> On the

<input type="checkbox"/> Via Email <input type="checkbox"/> Written Letters	<input type="checkbox"/> Via Email <input type="checkbox"/> Written Letters	Telephone <input type="checkbox"/> Via Email <input type="checkbox"/> Written Letters
--	--	---

Other (please explain): \_\_\_\_\_

**6. I have received messages that help me maintain a positive attitude from the patient's or my own:**

<b>Family:</b> <input type="checkbox"/> In person <input type="checkbox"/> On the Telephone <input type="checkbox"/> Via Email <input type="checkbox"/> Written Letters	<b>Friends:</b> <input type="checkbox"/> In person <input type="checkbox"/> On the Telephone <input type="checkbox"/> Via Email <input type="checkbox"/> Written Letters	<b>Acquaintances/Co-workers:</b> <input type="checkbox"/> In person <input type="checkbox"/> On the Telephone <input type="checkbox"/> Via Email <input type="checkbox"/> Written Letters
---	--	---

Other (please explain): \_\_\_\_\_

**7. Who has provided emotional or practical support to you or the patient? (check all that apply)**

	Emotional	Practical
The patient	<input type="checkbox"/>	<input type="checkbox"/>
Spouse/partner	<input type="checkbox"/>	<input type="checkbox"/>
Immediate Family	<input type="checkbox"/>	<input type="checkbox"/>
Relatives in town	<input type="checkbox"/>	<input type="checkbox"/>
Relatives out of town	<input type="checkbox"/>	<input type="checkbox"/>
Friends in town	<input type="checkbox"/>	<input type="checkbox"/>
Friends out of town	<input type="checkbox"/>	<input type="checkbox"/>
Co-workers	<input type="checkbox"/>	<input type="checkbox"/>
Members of my church/temple	<input type="checkbox"/>	<input type="checkbox"/>
Neighbors	<input type="checkbox"/>	<input type="checkbox"/>
Doctors or hospital staff	<input type="checkbox"/>	<input type="checkbox"/>
Other patients or caregivers	<input type="checkbox"/>	<input type="checkbox"/>
Other type of relationship (please explain):	<input type="checkbox"/>	<input type="checkbox"/>

Circle a number for each if the following questions:	Never → Frequently
8. Do you repeat news about the patient's health many times for different people?	1 2 3 4 5
9. Do you sometimes have trouble reaching people by phone to coordinate schedules or share information?	1 2 3 4 5
10. How often would you like to talk or socialize with your own...	
a. Family	1 2 3
b. Friends	4 5
c. Acquaintances/Co-workers	1 2 3

	4 5 1 2 3 4 5
11. How often do you <i>actually</i> talk or socialize with your own... a. Family b. Friends c. Acquaintances/Co-workers	1 2 3 4 5 1 2 3 4 5 1 2 3 4 5
	<b>No Desire → Strong Desire</b>
12. Would you like to get advice and support from other patients or caregivers	1 2 3 4 5
13. Do you want to encourage cancer prevention with other people?	1 2 3 4 5

## Personalized Web Pages and E-mail Tools

We will use your responses to the previous questions to help us design personalized web pages and e-mail tools that can help patients and informal caregivers with their cancer-related communication and information needs.

On the condition that the system will be completely private and secure, and that you will have full control of your own personal information, would you potentially use such a system for the following scenarios?

	No Desire → Strong Desire			
1. Emailing questions from home to the patient's doctors or hospital staff	1	2	3	4
	5			
2. Keeping lists of questions to ask the doctors during the visit	1	2	3	4
	5			
3. Reviewing information or instructions given by the doctors during a visit	1	2	3	4
	5			
4. Learning techniques for managing the patient's pain and symptoms	1	2	3	4
	5			
5. Recording and tracking the patient's pain levels and symptoms	1	2	3	4
	5			
6. Helping you initiate difficult and awkward conversations with...	1	2	3	4
a. the patient	5			
b. doctors or hospital staff	1	2	3	4
c. family, friends, or co-workers	5			
	1	2	3	4
	5			
7. Updating family, friends, or co-workers about the patient's health or activities	1	2	3	4
	5			
8. Keeping in touch socially with your own family, friends, or co-workers	1	2	3	4
	5			
9. Keeping a private journal or diary for yourself	1	2	3	4
	5			
10. Educating family, friends, and others about cancer	1	2	3	4
	5			
11. Encouraging cancer prevention with family and friends	1	2	3	4
	5			
12. Sending messages to family/friends/co-workers while waiting in the clinic...	1	2	3	4
a. To coordinate schedules or tasks that need to get done back home	5			
b. To let them know how the visit is going	1	2	3	4
	5			
13. Receiving text-message alerts on my cell phone from...	1	2	3	4
a. the patient	5			
b. doctors or hospital staff	1	2	3	4
c. family, friends, or co-workers	5			
	1	2	3	4
	5			
14. Sharing advice and supportive messages with other patients or caregivers	1	2	3	4
	5			
15. Describe any other types of informational or communication support that you desire, in addition to those listed above, on the back of this page.				
<b>Thank you for completing this survey. Your answers will help us design systems that can improve communication between doctors, patients, and family/friends caregivers.</b>				

## Patient Phrasing:

### Family Geography and Demographics

10. Does a family or friend caregiver live with you?  
 Yes  No
11. How many of your close friends or relatives live in the same town or city as you?  
 None  A few of them  Most of them  All of them
12. How long does it take you to travel to the Vanderbilt-Ingram Cancer Center?  
\_\_\_\_\_ hours, \_\_\_\_\_ minutes
13. How often do you come to the Vanderbilt-Ingram Cancer Center for treatment?  
 Daily  Weekly  Monthly  Other: \_\_\_\_\_
14. What is your age (in years): \_\_\_\_\_
15. What is your gender?  Male  Female
16. Describe your racial group:  
 White (Non Hispanic)  Hispanic or Latin Origin  
 African American  Bi-racial: \_\_\_\_\_  
 Asian/Pacific Islander  Other: \_\_\_\_\_

### Internet and Telephone

6. In the past week, I used... (check all that apply)  
 Telephone  Email  Web pages  
 Instant Messaging (IM)  "Text Messaging" on a cell phone
7. Do you carry a cell phone when you leave home?  
 Yes  No
8. Do you have Internet access at work?  
 Yes  No
9. Do you have Internet access at home?  
 Yes  No  
→ If 'Yes,' is it:  dial-up or  broadband (cable/dsl) or  don't know
10. How many of your close friends and relatives use the Internet or email?  
 0  1-2  3-4  5 or more  Don't know

## Pain and Symptom Management / Asking Doctors Questions

5. **How do you remember questions or concerns to discuss with the doctor during the visit** (*check all that apply*)
- I write a list of questions on paper
  - A friend or family member writes a list of questions on paper
  
  - I remember the questions, without writing anything down
  - A friend or family member helps me remember concerns to discuss with the doctor
  
  - Other, please explain:
6. **How do you remember what the doctor tells you during the visit** (*check all that apply*)
- I take notes during the visit
  - A friend or family member takes notes during the visit
  
  - I remember without writing anything down
  - A friend or family member helps me remember
  
  - I write up notes after I get home
  - A friend or family member writes up notes after we get home
  
  - Other, please explain:
7. **How do you currently help keep track of your pain levels at home** (*check all that apply*)
- I write notes in a journal or chart:  **Hourly**    **Daily**    **Weekly** (*check how often*)
  - I only write a note when there is a significant change
  - I just make a mental note
  - I ask someone else to handle this for me
  - Other, please explain:
8. **How do you currently keep track of your other symptoms at home** (*check all that apply*)
- I write notes in a journal or chart:  **Hourly**    **Daily**    **Weekly** (*check how often*)
  - I only write a note when there is a significant change
  - I just make a mental note
  - I ask someone else to handle this for me
  - Other, please explain:

Circle a number for each of the following statements:	Never → Frequently
5. During the visit, I forget to ask the doctor certain questions	1 2 3 4 5
6. During the visit, I am embarrassed to ask the doctor certain questions	1 2 3 4 5
7. After the visit, I forget the instructions or information that the doctor tells me	1 2 3 4 5
8. I need more information about managing... a. my pain b. my other symptoms c. side effects from the chemotherapy or other medicines	1 2 3 4 5 1 2 3 4 5 1 2 3 4 5
<b>Strongly Disagree → Strongly Agree</b>	
9. If I could ask questions in writing, I would ask the doctors more sensitive or embarrassing questions	1 2 3 4 5
10. I hope the doctor would bring up my... a. <i>emotional</i> concerns b. <i>practical</i> concerns	1 2 3 4 5 1 2 3 4 5
11. I believe the patient or informal caregiver should bring up... a. <i>emotional</i> concerns b. <i>practical</i> concerns	1 2 3 4 5 1 2 3 4 5

**READ THESE DEFINITIONS BEFORE CONTINUING:**

**In the next section, you will be asked about how you communicate with Family, Friends, and Acquaintances/Co-workers:**

- **“Family”** means your partner/spouse, and your immediate families and relatives.
- **“Friend”** means someone with whom you choose to share a close bond. This is someone outside of your family in whom you can confide and discuss personal issues and concerns.
- **“Acquaintance/Co-worker”** means someone with whom you socialize, keep in touch, or see on a regular basis, but with whom you do not share a close personal bond. Your casual friends, neighbors, and other members of the community would fall into this category.

## Talking about cancer and care needs with family, friends, and others

Check only the answers that apply to you:

### 8. I give general updates about my activities to my:

<b>Family:</b>	<b>Friends:</b>	<b>Acquaintances/Co-workers:</b>
<input type="checkbox"/> In person	<input type="checkbox"/> In person	<input type="checkbox"/> In person
<input type="checkbox"/> On the Telephone	<input type="checkbox"/> On the Telephone	<input type="checkbox"/> On the Telephone
<input type="checkbox"/> Via Email	<input type="checkbox"/> Via Email	<input type="checkbox"/> Via Email
<input type="checkbox"/> Written Letters	<input type="checkbox"/> Written Letters	<input type="checkbox"/> Written Letters

Other (please explain): \_\_\_\_\_  I ask someone else to handle this for me

### 9. I discuss specific details of my treatment with my:

<b>Family:</b>	<b>Friends:</b>	<b>Acquaintances/Co-workers:</b>
<input type="checkbox"/> In person	<input type="checkbox"/> In person	<input type="checkbox"/> In person
<input type="checkbox"/> On the Telephone	<input type="checkbox"/> On the Telephone	<input type="checkbox"/> On the Telephone
<input type="checkbox"/> Via Email	<input type="checkbox"/> Via Email	<input type="checkbox"/> Via Email
<input type="checkbox"/> Written Letters	<input type="checkbox"/> Written Letters	<input type="checkbox"/> Written Letters

Other (please explain): \_\_\_\_\_  I ask someone else to handle this for me

### 10. I have asked for practical help, or I received offers for help from:

<b>Family:</b>	<b>Friends:</b>	<b>Acquaintances/Co-workers:</b>
<input type="checkbox"/> In person	<input type="checkbox"/> In person	<input type="checkbox"/> In person
<input type="checkbox"/> On the Telephone	<input type="checkbox"/> On the Telephone	<input type="checkbox"/> On the Telephone
<input type="checkbox"/> Via Email	<input type="checkbox"/> Via Email	<input type="checkbox"/> Via Email
<input type="checkbox"/> Written Letters	<input type="checkbox"/> Written Letters	<input type="checkbox"/> Written Letters

Other (please explain): \_\_\_\_\_

### 11. I have given or received information about cancer and treatments from:

<b>Family:</b>	<b>Friends:</b>	<b>Acquaintances/Co-workers:</b>
<input type="checkbox"/> In person	<input type="checkbox"/> In person	<input type="checkbox"/> In person
<input type="checkbox"/> On the Telephone	<input type="checkbox"/> On the Telephone	<input type="checkbox"/> On the Telephone
<input type="checkbox"/> Via Email	<input type="checkbox"/> Via Email	<input type="checkbox"/> Via Email
<input type="checkbox"/> Written Letters	<input type="checkbox"/> Written Letters	<input type="checkbox"/> Written Letters

Other (please explain): \_\_\_\_\_

### 12. I have discussed my emotions about my cancer with:

<b>Family:</b>	<b>Friends:</b>	<b>Acquaintances/Co-workers:</b>
<input type="checkbox"/> In person	<input type="checkbox"/> In person	<input type="checkbox"/> In person
<input type="checkbox"/> On the Telephone	<input type="checkbox"/> On the Telephone	<input type="checkbox"/> On the Telephone
<input type="checkbox"/> Via Email	<input type="checkbox"/> Via Email	<input type="checkbox"/> Via Email
<input type="checkbox"/> Written Letters	<input type="checkbox"/> Written Letters	<input type="checkbox"/> Written Letters

Other (please explain): \_\_\_\_\_

13. I have received messages that help me maintain a positive attitude from:

<b>Family:</b>	<b>Friends:</b>	<b>Acquaintances/Co-workers:</b>
<input type="checkbox"/> In person	<input type="checkbox"/> In person	<input type="checkbox"/> In person
<input type="checkbox"/> On the Telephone	<input type="checkbox"/> On the Telephone	<input type="checkbox"/> On the Telephone
<input type="checkbox"/> Via Email	<input type="checkbox"/> Via Email	<input type="checkbox"/> Via Email
<input type="checkbox"/> Written Letters	<input type="checkbox"/> Written Letters	<input type="checkbox"/> Written Letters

Other (please explain): \_\_\_\_\_

14. Who has provided emotional or practical support? (check all that apply)

	<b>Emotional</b>	<b>Practical</b>
Spouse/partner	<input type="checkbox"/>	<input type="checkbox"/>
Immediate Family	<input type="checkbox"/>	<input type="checkbox"/>
Relatives in town	<input type="checkbox"/>	<input type="checkbox"/>
Relatives out of town	<input type="checkbox"/>	<input type="checkbox"/>
Friends in town	<input type="checkbox"/>	<input type="checkbox"/>
Friends out of town	<input type="checkbox"/>	<input type="checkbox"/>
Co-workers	<input type="checkbox"/>	<input type="checkbox"/>
Members of my church/temple	<input type="checkbox"/>	<input type="checkbox"/>
Neighbors	<input type="checkbox"/>	<input type="checkbox"/>
Doctors or hospital staff	<input type="checkbox"/>	<input type="checkbox"/>
Other patients or caregivers	<input type="checkbox"/>	<input type="checkbox"/>
Other type of relationship (please explain):	<input type="checkbox"/>	<input type="checkbox"/>

Circle a number for each if the following questions:	<b>Never → Frequently</b>
8. Do you repeat news about your health many times for different people?	1 2 3 4 5
9. Do you sometimes have trouble reaching people by phone to coordinate schedules or share information?	1 2 3 4 5
10. How often would you <i>like</i> to talk or socialize with your own... a. Family b. Friends c. Acquaintances/Co-workers	1 2 3 4 5 1 2 3 4 5 1 2 3 4 5
11. How often do you <i>actually</i> talk or socialize with your own... a. Family b. Friends	1 2 3 4 5 1 2 3 4 5 1 2 3 4 5

c. Acquaintances/Co-workers	
	<b>No Desire → Strong Desire</b>
12. Would you like to get advice and support from other patients or caregivers	1 2 3 4 5
13. Do you want to encourage cancer prevention with other people?	1 2 3 4 5

## Personalized Web Pages and E-mail Tools

We will use your responses to the previous questions to help us design personalized web pages and e-mail tools that can help patients and informal caregivers with their cancer-related communication and information needs.

On the condition that the system will be completely private and secure, and that you will have full control of your own personal information, would you potentially use such a system for the following scenarios?

	No Desire → Strong Desire		
1. Emailing questions from home to doctors or hospital staff	1 4	2 5	3
2. Keeping lists of questions to ask the doctors during the visit	1 4	2 5	3
3. Reviewing information or instructions given by the doctors during a visit	1 4	2 5	3
4. Learning techniques for managing your pain and symptoms	1 4	2 5	3
5. Recording and tracking your pain levels and symptoms	1 4	2 5	3
6. Helping you initiate difficult and awkward conversations with... a. doctors or hospital staff b. family, friends, or co-workers	1 4 4	2 5 5	3 3 3
7. Updating family, friends, or co-workers about your health or activities	1 4	2 5	3
8. Keeping in touch socially with your family, friends, or co-workers	1 4	2 5	3
9. Keeping a private journal or diary for yourself	1 4	2 5	3
10. Educating family, friends, and others about cancer	1 4	2 5	3
11. Encouraging cancer prevention with family and friends	1 4	2 5	3
12. Sending messages to family/friends/co-workers while waiting in the clinic... a. To coordinate schedules or tasks that need to get done back home b. To let them know how the visit is going	1 4 4	2 5 5	3 3 3
13. Receiving text-message alerts on my cell phone from... a. doctors or hospital staff b. family, friends, or co-workers	1 4 4	2 5 5	3 3 3
14. Sharing advice and supportive messages with other patients or caregivers	1 4	2 5	3
15. Describe any other types of informational or communication support that you desire, in addition to those listed above, on the back of this page.			
<p><b>Thank you for completing this survey. Your answers will help us design systems that can improve communication between doctors, patients, and family/friends caregivers.</b></p>			

## APPENDIX B

### STRUCTURED INTERVIEW QUESTIONS

#### **Communicating with doctors:**

- Describe the most difficult practical challenges of keeping track of the patient's pain or symptoms at home.
  - Describe any creative methods you use to keep track of the patient's pain or symptoms at home.
  - What can make it hard to describe or discuss the pain and symptoms to the doctor?
  
- Describe situations about which you would like more information or advice from the doctor during the visit.
  - If you have a concern or don't know what to do about something at home, how do you decide whether or not to call a doctor in the cancer clinic?
  - What do you do if you don't call the doctor?

#### **Family Communication**

- Describe the methods you use to keep family and friends informed of how you and the patient are doing.
  - Telephone? E-mail? Other?
  
- Describe the different ways that family, friends, or others have helped you with handling the cancer treatment...
  - Emotional support? Practical support?

#### **Use of Internet/Interest in Internet Tools:**

- Describe your current use of Internet or E-mail: in general, and related to cancer

*If they do use E-mail or the Internet to communicate:*

- Describe how you use E-mail or the Internet to communicate with family, friends, or others since you started treatment?
  - What do you send/receive messages about?
  - Describe times during your treatment when E-mail has made it easier to communicate compared to using the telephone.
  
- If you had a wish list about informational and communication needs that you would like improved, what would you put on the list?
  - For dealing with doctors...
    - Would you use a personal web site that could solve these issues?
    - What would make you hesitate in using a site for these issues?
  - For dealing with family, friends, or others...

- Would you use a personal web site that could solve these issues?
- What would make you hesitate in using a site for these issues?

## APPENDIX C

### RELATIONSHIP-CENTRIC DESIGN FRAMEWORK

# Online Communication and Support for Cancer Patients: A Relationship-centric Design Framework

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#### Abstract

Dealing with a cancer diagnosis and cancer treatment involves communication among clinicians, patients, families, friends and others affected by the illness. The hypothesis of this research is that an informatics system can effectively support the communication needs of cancer patients and their informal caregivers. Two design frameworks for online cancer communication are defined and compared. One is centered primarily on the users' interpersonal relationships, and the other is centered on the clinical data and cancer information. Five types of clinical and supportive relationships were identified and supported by in-depth interviews with cancer patients and their informal caregivers. Focusing the design of an online cancer communication system around the interpersonal relationships of patients and families may be an important step towards designing more effective paradigms for online cancer care and support.

#### Introduction

Patient-controlled Personal Health Records (PHRs) and patient-provider communication systems are recognized as essential components of emerging web-based paradigms for patients' involvement in the management of their own health care.<sup>1</sup> Web-based information and communication systems for cancer patients have demonstrated that personalized, interactive systems can increase the patients' confidence in their care and improve social support.<sup>2</sup> However, a review of online cancer patient support groups found that the existing research is inconclusive about significant overall benefits of online cancer communities.<sup>3</sup>

Dealing with the diagnosis of cancer and managing the treatment involves complex and very personal information and communication

needs among clinicians, patients, families, friends and others affected by the illness.<sup>4</sup> Because of these complex needs, recent treatment plans for cancer aim to focus on the patient as a whole, involving components for physical, emotional, spiritual, and social care and support.<sup>5</sup> In practice, many of these needs still are unmet by health-care providers.<sup>6</sup>

The subtle aspects of holistic cancer care and communication must be handled in emerging online cancer communication systems in order to achieve the highest quality standard of care in an online environment. Clinical and supportive systems have begun to address the online communication needs of patients and families, but novel design approaches are needed to fully realize the potential of holistic care features in online cancer communication.

Two design frameworks are defined and compared. One is centered primarily on the users' interpersonal relationships, and the other is centered on the clinical data and cancer information.

#### Two Design Frameworks

##### *Relationship-centric design*

Relationship-centric design follows two principles:

1. Interpersonal relationships between the users are the basic units around which all other components in the design are framed.
2. The social influences in the relationships are understood and are addressed in the design.

The emphasis in this design is on the individuals and groups using the system and how they interact in their relationships. The relationships might exist entirely within the online system, or they may continue offline

through in-person and telephone-based communication. Relationship-centric design seeks to understand the roles and influences of the people who share information on the system. The information content on the system is represented within the context of these relationships.

#### *Information-centric design*

Information-centric design stresses the information exchanged, with minimal emphasis on the relationships between the users. This approach follows the general principle:

The information and structured content are the basic units around which all other components in the design are framed.

The highly-structured requirements of sharing medical data, symptom tracking, medication lists, and other records may lead developers to create a design that centers on each user's information needs. This is representative of an information-centric design. Relationship-centric design does not ignore these needs; rather, it attempts to satisfy them in context of the social influences between/among the users.

Relationship-centric design and information-centric design are not mutually exclusive frameworks for online communication systems. An information-centric design is, in a sense, a relationship-centric design that is stripped of all interpersonal associations between the users. A design becomes more relationship-centric as more emphasis is placed on the users' interpersonal relationships. This balance between the users' relationships and the information content relates to Coiera's work on the critical interplay between communication and information in an organization's clinical information system.<sup>7</sup> Relationship-centric design expands upon the notion of communication-centric design by more actively addressing the social influences that shape the communication in each user's personal relationships.

#### *Why use a relationship-centric design for online cancer communication?*

The fundamental concepts of relationship-centric design are informed by the field of social psychology. Social psychology is defined as "the scientific study of the way in which people's thoughts, feelings, and behaviors are influenced by the real or imagined presence of others."<sup>8</sup> Social norms and other pressures directly and indirectly influence interpersonal actions in the

real-world. Suler suggests that well-studied social psychology principles can be applied to the study of online communities and new principles of social psychology may be created to address the uniqueness of online relationships.<sup>9</sup> In cancer communication, for example, a patient might not ask a provider for pain medicine if he or his family fears an addiction or if he wants to be a 'good' patient in the patient-provider relationship.<sup>10</sup> A relationship-centric design incorporates an understanding of *why* the patient is *not* asking his provider for pain medicine, whereas a purely information-centric design will provide only structured interfaces for the user to request medication.

The cancer patient and family face the illness in the context of their existing responsibilities and relationships. Given and Given argue for the use and creation of more family-focused care plans for cancer treatment.<sup>4</sup> The unique communication and support needs suggest that an online communication system for cancer care should not neglect the holistic aspects of the in-person care and support. Figure 1 illustrates the clinical and social relationships of a cancer patient, primary caregiver, family and friends, and fellow patients. A relationship-centric design for holistic cancer communication will address each of these relationships as desired by the patient.

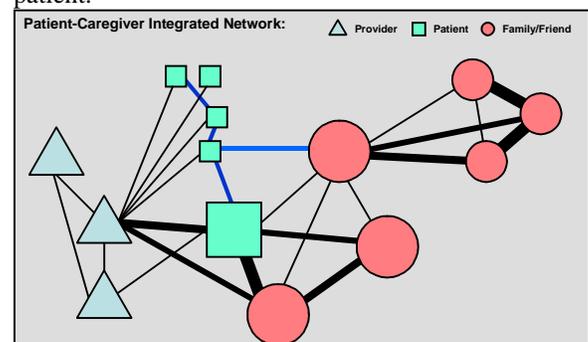


Figure 1: Patient-Caregiver Integrated Network. The thickness of the lines represents the complexity and uniqueness of each relationship.

#### **Research Methodology**

The research methodology for the entire study will consist of three major phases. Phase I focuses on understanding the communication needs of the cancer patients and caregivers. Phase II will be the design of the system and Phase III will be field testing the system. This paper covers only the interview portion of the initial assessment phase that provided the context for the design of the system (Phase II).

### *Patient and Caregiver Interviews*

Semi-structured, 30-60 minute interviews were conducted over the course of one week with sixteen patients receiving chemotherapy in the Vanderbilt-Ingram Cancer Center clinic. There were no follow-up interviews. Nine of the sixteen patients had a family or friend caregiver who participated in the interview. The patients were all adults with various cancer diagnoses, including head and neck, lung, and breast cancers. The interviews focused on communication needs with the clinic (e.g. "Describe the practical challenges of keeping track of your/the patient's pain or symptoms at home."), clinical and supportive communication needs with family and friends (e.g. "Describe the methods you use to keep family and friends informed of how you and the patient are doing."), and general use and interest in the Internet for cancer communication (e.g. "About what do you send/receive messages online?"). Saturation was reached after sixteen interviews.

### **Results**

The interviews were transcribed and were coded into 73 non-hierarchical concept nodes with the N6 software package using a modified grounded theory methodology. Five types of clinical and supportive relationships were identified from the concepts, which were labeled based on topics mentioned and descriptive characteristics of each interview response. These five classes of relationships are Clinical, Explicit Supportive, Implicit Supportive, Private-Open, and Holistic relationships. For each relationship, information-centric and relationship-centric designs are compared as to how they wouldn't address the communication needs.

#### *Clinical Relationships*

Informal family and friend caregivers are involved actively in the patient's clinical care both at home and during the clinic visits.<sup>4</sup> A patient's brother visiting from out of town described how he has been active in the clinical care:

About the time he was finishing up his treatments that made me think we had missed some instructions during that period of time, because it didn't seem like we were fully compliant. [...] Well, I came back, and we asked a lot of questions, and we made some notes and found out exactly what he should be doing for his nutrition, got him on a

schedule. And, so he has his schedule, and he does that for himself now.

From an information-centric approach, the focus of the provider's patient communication system is on providing treatment information, structured symptom tracking and decision support, patient education, and responding to the patients' questions. The patients may be sharing this information or getting advice from family and friends regarding the questions they ask, but these informal consultations are not facilitated or documented in the clinical messaging system.

In a relationship-centric design, the goal of the clinical communication is to appropriately include all people that the patient defines as partners in his or her clinical care and to understand what type of clinical communication is involved in each of these relationships. Who needs to know every detail of the clinical care in monitoring and assisting with the home care? With whom do the patients and primary caregivers consult for certain types of assistance?

Detailed information, provider messaging, and tools for symptom tracking and decision support all may be included in the design of the system. But, in a relationship-centric approach, these components are designed to include and support all of the formal and informal relationships that the patient chooses to involve in each clinical activity. For example, the design could include conversation spaces shared by the patient, selected family members, and the clinic's nutritionist, social worker, and/or spiritual nurse.

#### *Explicit Supportive Relationships*

Family and friends directly support the patient in many of the non-clinical communication needs associated with facing the illness and receiving cancer treatment.<sup>4</sup> This may include practical support such as arranging rides to the clinic visits and running errands. Family communication also may involve active emotional support, such as visiting the patient in the home and listening to the patient's concerns. Family and friends also may provide informational support, such as helping the patient or primary caregivers find information about cancer, treatment options, side effects, or other general resources.

Much of the literature on supportive cancer care provides examples of explicit support, and the patients and/or caregivers in each interview provided personal examples of this support from family, friends, and also from other patients.

Studies of existing online cancer support groups have found that messages shared are related to emotional and social support as well as to the exchange of clinical information.<sup>11</sup>

A relationship-centric cancer communication system would include the family and friends who have supportive relationships with the patient, even if they do not have active clinical relationships with the patient or the clinic team. The patient still has communication needs with these family members and friends. A relationship-centric design would address the communication needs of the family's clinical relationships while not ignoring the context of the supportive communication needs, and vice versa. An information-centric design would not attempt to deal with the overlaps and influences between the clinical and non-clinical relationships.

#### *Implicit Supportive Relationships*

Implicit supportive relationships refer to the perceived presence of family, friends, fellow patients, and providers; a sense of support during the times that they aren't engaged in explicit support and communication. Eight (50%) of the interviewed patients and caregivers described their supportive relationships as 'knowing that they're there,' even when there is no current need for active support:

"That's really the important thing [...] especially with families, you know, they care and they are interested [...]"

"Well, we know, when we ask, they will come. That's the kind of friends that we have."

Information-centric designs and relationship-centric designs will differ in their approaches to addressing these implicit communication needs in the online system. Perceived presence of support does not involve the sharing of any hard data, so an information-centric framework may pass over these subtle aspects of supportive communication.

A relationship-centric design would incorporate the essence of these silent and implied interactions into many interfaces throughout the communication system. Understanding and incorporating aspects of the relationships that cannot easily be expressed in words is fundamental to the relationship-centric design framework.

One of the interviewed patients created her own public web site on which she shared her treatment news and family updates. She looked into putting a visit counter on her site, "because I really would love to know, how many people are

going out there." The feedback of knowing that someone is listening, which occurs during in-person and telephone-based conversations, is not a standard in most web-based communications. The implicit support of the listener can play an essential role in the two-way relationship, and providing an indication of this activity to the patient online could be done in many simple and creative ways. In an information-centric design, this type of feedback may be a nice feature to include for receipt confirmation, but in a relationship-centric design this type of feedback is tightly integrated with each component of the system. For instance, the names and pictures of recent visitors to the patient's web site could be displayed at each patient login.

#### *Private and Open Relationships*

During the interviews, each patient expressed unique privacy needs regarding communication about his or her illness. All of the patients and caregivers were open about their well-being and general treatment information with most family and friends who expressed interest. Three patients (19%) shared information with friends but kept details from certain family members. One patient said she would not mind if her children asked questions to the doctor if they did not feel comfortable asking her directly. As a whole, the patients have unique inclusion and exclusion criteria for sharing different details with different individuals and groups. Also, patients, family members, and friends may desire to share more emotional messages in a private setting, whereas they don't mind sharing general supportive messages in a more open, public setting.

An information-centric design will focus mainly on the patient's data and may not fully address the different levels of privacy or openness in which the information is shared. A relationship-centric design will provide a means for the patient to selectively share the information in ways that are appropriate for each individual and group relationship. Research in Personal Health Records involves this aspect of relationship-centric design.<sup>12</sup> The patient is given control over who can view and access his or her information stored in the record, based on the requesting user's identity, role, or other relation to the patient. This user-defined control of sharing personal information typically refers to the exchange of Protected Health Information with health care providers. In addition to giving the patient control over clinical information, an analogous approach can allow the patient to

selectively share certain emotional and personal messages with friends, family, and others.

### *Holistic Relationships*

The interviews provided several examples of ways in which communication about the illness blends with the context of the patients' daily lives.

The daughter of one patient keeps a notebook in which she records how her mother is feeling, what has occurred in the clinic, and what to expect related to her mother's treatment. The daughter also uses the same notebook to keep a journal for herself about her own life. For her, there is no real distinction between her clinical notes and her personal notes,

It's my journal. It's my composition, what goes on with my life, just different things that happen. [...] my whole life, this is my journal, and she's my life.

An information-centric design might provide an area for clinical messages and journals, but it would not address this relationship between the clinical information and the patient's or caregiver's need to record and/or share other types of personal information alongside the clinical notes.

Another patient explained that she uses the phone to update her family on her treatment, and she added,

But still, you know, we could talk about other things, instead of all of this. I mean, don't get me wrong, this is important, and it's really a big factor in my life, but it's not the only thing I want to talk about. So if I just would cover the other [online], and then if the doctor has a specific something or other that needs to be shared with the family, you know, that could be done too.

Even though many of the patient's communication needs may focus on cancer, she does not want this communication to overshadow and take away from the other meaningful aspects of her relationships. She suggests that if she could share some of the clinical discussions online, she would have to repeat herself less often and have more time to talk about other topics with her family.

But online clinical communication may produce unintended effects on the patient's non-clinical, social relationships. The patient who created her own web site mentioned concerns that apart from her immediate family, it seems

like people tend just to read the web site, and they do not call her to talk on the telephone as much as she would like.

When an online communication system is introduced, the default, most convenient mode of communicating with the patient may change, even if this is not desirable for the patient at all times. It is important to design the cancer communication system so that it does not inadvertently impact other aspects of a patient's relationships in a negative manner. An information-centric design would aim to share the primary treatment news efficiently, while a relationship-centric design would attempt to recognize how the online clinical communication affects other aspects of the patient's interpersonal interactions.

### **Discussion**

One design of a patient-provider messaging system is to center the communication channels on the relationships and communication needs of the providers, where communication with the patient is one of those connections. The patient is viewed as an isolated end-user in the clinical system, rather than as a person with relationships and influences outside of the clinic team. This design may be a natural model for a health care organization's existing clinical information system, but it does not accurately represent the patient's communication needs in the broad context of his or her illness.

Another way to design the system is to center it on each patient, where the health care provider is one of the several communication channels utilized by the patient. In this design, it is critical for the providers to actively participate in the communication system, because they are a main partner in the patient's care. The providers must also recognize and address the fact that the patient and family have other communication needs and influences during the illness. This design may involve collaborations within or outside of the health care system, and it is a natural and necessary strategy for cancer communication systems to fully address all of the patients' communication needs.

Relationship-centric design can inform the development of a communication system for cancer patients with two distinctive characteristics:

1. Each user has the option to invite and define relationships and privacy with his or her own family and friends
2. The system includes various forms of implicit feedback with both clinical and

non-clinical communication between providers, patients, and family/friends

### **Conclusion**

Relationship-centric design for online cancer communication has the potential to help developers create new paradigms that better reflect the broad network of care and the holistic nature of in-person cancer care and support. Developers of cancer communication systems, and perhaps developers of all patient communication systems, should attempt to address more of the patients' outside relationships that may influence or be affected by the online clinical communication with the health care team.

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## APPENDIX D

### CONCEPT NODES FROM INTERVIEW RESPONSES

The 73 Concept Nodes from N6 Software for the Phase I results, prior to organization into hierarchical categories, as presented earlier.	
<ol style="list-style-type: none"> <li>1. trouble remembering symptoms</li> <li>2. prefers computers/typing</li> <li>3. a central/easy place to store things</li> <li>4. assistance of spouse/immediate family</li> <li>5. memory not as good now</li> <li>6. symptom sheet is helpful</li> <li>7. routine symptoms/side effects (remember if new)</li> <li>8. knowing when to call doctors</li> <li>9. email vs. phone vs. in person</li> <li>10. family/friend types of info shared/asked</li> <li>11. prayer/church</li> <li>12. patient to patient</li> <li>13. don't want surprises</li> <li>14. online searching/use for cancer info</li> <li>15. views on using a web system</li> <li>16. hesitations</li> <li>17. desire/idea for the system</li> <li>18. family size/social support situation</li> <li>19. lucky/not much pain or symptoms/normal activities</li> <li>20. writing/journaling/tracking</li> <li>21. doctors at Vanderbilt know what they're doing</li> <li>22. help the doctors help you</li> <li>23. questions/needs/misunderstandings of family/friends</li> <li>24. getting questions answered with doctors</li> <li>25. notes/question lists</li> <li>26. family understanding the procedure</li> <li>27. early vs. with practice</li> <li>28. calling or email with doctors</li> <li>29. emotional support</li> <li>30. practical support</li> <li>31. informational support</li> </ol>	<ol style="list-style-type: none"> <li>36. control over something</li> <li>37. private expression</li> <li>38. nutrition</li> <li>39. mental cues to trigger questions</li> <li>40. medicines questions</li> <li>41. side effect info</li> <li>42. symptoms make it hard to talk on phone</li> <li>43. nurses too</li> <li>44. about my specific case</li> <li>45. Uses web tools already</li> <li>46. lab results wanted</li> <li>47. social support</li> <li>48. overlap of health and general life</li> <li>49. dangers of changing communication patterns</li> <li>50. friends of friends</li> <li>51. personal web site</li> <li>52. different groups different messages</li> <li>53. feedback on who read/presence</li> <li>54. humor/excitement expressions</li> <li>55. schedules</li> <li>56. didn't think it was important</li> <li>57. could learn how to use it</li> <li>58. different doctors, different needs</li> <li>59. forgetting to ask in visit</li> <li>60. keep it brief</li> <li>61. prescriptions</li> <li>62. questions about the cancer itself</li> <li>63. doctors don't give some info</li> <li>64. like to hear good things</li> <li>65. financial</li> <li>66. personal connection with care provider</li> <li>67. positive attitude</li> <li>68. general internet/computer use</li> <li>69. text messages</li> <li>70. don't want to bother doctors</li> </ol>

32. loose or tight privacy	71. chemo/procedure questions
33. you know they're there	72. prevention
34. Trust in Vanderbilt (and the doctors/nurses)	73. desire to help
35. incomplete interview	

APPENDIX E

ONLINE SURVEY RESPONSES

**Jennifer's Responses:**

**1) Do you have Internet access at home?**

Yes

2) broadband (cable or dsl)

**3) Where have you logged into this system? (check all that apply)**

Home

**4) How many of your close friends and relatives use the Internet or email?**

5 or more

**5) How often do you come to the Vanderbilt-Ingram Cancer Center for treatment?**

Weekly

soon to be daily when I start radiation around the first of August

**6) Describe your relation to the patient**

I am the patient

**7) Are you the primary family/friend caregiver?**

No

**8) Do you live in the same home as the patient?**

Yes

**9) How many of your close friends or relatives live in the same town or city as you?**

A few of them

**10) How long does it take you to travel to the Vanderbilt-Ingram Cancer Center?**

one hour fifteen minutes

**11) What aspects of the system did you find most useful or pleasing to use?**

Being able to send the same message to many of my friends who are out of state because we just moved to [a new state]. Also, being able to contact my support team in case of a general question which does not need immediate emergency attention. I appreciated Jacob's patience. There were days when I should have answered faster, but because I wasn't feeling really good, I'd put it off a day or two. Jacob always understood and did not interfere with my rest time. Nice job.

**12) What aspects of the system were hard to use? What would you like to see changed or improved?**

I have used my private space the least. I'm still not sure who can have access to it. I write in a book journal and feel more private. Some of the terminology was a little different. But, Jacob and I worked through most of it. I really enjoy coming to my computer and checking for messages everyday. Not all of my friends e-mail me through this system, they just use the regular e-mail. I think that I will use this more when I start my radiation and lose my voice and have a sore throat. In fact, I may be doing a lot of my talking this way. This is a great project. I'm looking forward to meeting some other patients, but I don't know how to get a hold of them? And, most of all we need a SPELL CHECK. Let me know if I need to answer anymore questions. Thanks.

**13) Did you ever feel uncomfortable writing something on the system? What made you hesitate to use the system for certain types of messages or notes?**

Just as I said before. Only the private journal part. I have a very personal question, I need to ask my doctor, but I would not want to put it on the treatment team section yet. I'm not sure who has access to these questions.

**14) Are the messages you share on the system different from the kinds of messages or conversations you have on email or the telephone? Please explain.**

Yes, so far they are more general. I can tell a number of people at one time how I am doing. If it is a personal individual e-mail, I can make it more personal and relevant to their knowledge. But, it saves me a lot of time. I was having to answer sometimes 30 e-mails and that was way to much for my energy level.

**15) This system allows the patient or primary caregiver to communicate with the clinic and also with the family and friends from the same web site? Do you think that this combined design is preferable, or would you rather have two independent web sites for each type of communication? Please explain.**

Good question. Now, my e-mail pals can't ask my doctor's questions can they? This would overburden the doctors. I have only one person, my husband's brother, who as you know is a physician radiologist himself, who I want to be able to communciate with [the radiologist] when I get into radiation. I'm not sure if he is keyed into this part of the program or not. Otherwise, no one else needs to talk to the doctors unless, I designate one of my four sons so he can sort of be a spokesman for his other brothers. I don't want to over tax the physicians. I don't know how they do what they do now. I am so completely satisfied with the service they provide at Vanderbilt.

**Tom's Responses:**

**1) Do you have Internet access at home?**

Yes

**2) broadband (cable or dsl)**

**3) Where have you logged into this system? (check all that apply)**

Home

**4) How many of your close friends and relatives use the Internet or email?**

5 or more

**5) How often do you come to the Vanderbilt-Ingram Cancer Center for treatment?**

Weekly

**6) Describe your relation to the patient**

Partner/Spouse

**7) Are you the primary family/friend caregiver?**

Yes

**8) Do you live in the same home as the patient?**

Yes

**9) How many of your close friends or relatives live in the same town or city as you?**

A few of them

**10) How long does it take you to travel to the Vanderbilt-Ingram Cancer Center?**

1 hour

**11) What aspects of the system did you find most useful or pleasing to use?**

comfort level having closer communication with medical staff

**12) What aspects of the system were hard to use? What would you like to see changed or improved?**

Logging in. Not systems fault, I am just a slow learner

**13) Did you ever feel uncomfortable writing something on the system? What made you hesitate to use the system for certain types of messages or notes?**

no

**14) Are the messages you share on the system different from the kinds of messages or conversations you have on email or the telephone? Please explain.**

No, not really

**15) This system allows the patient or primary caregiver to communicate with the clinic and also with the family and friends from the same web site? Do you think that this combined design is preferable, or would you rather have two independent web sites for each type of communication? Please explain.**

At this point in time, the same web site is fine.

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