Technology Preferences and Routines for Distributed Families Coping with a Chronic Illness

by

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Abstract

Most family members want to stay aware of each other’s activities on an ongoing basis to maintain a sense of connectedness. In situations where a family member is ill, the desire to stay connected increases, as many families face the challenges of coping with the diagnosis and treatment of a chronic illness. Previous research has evaluated technologies designed to support patients and caregivers with personal health information management and sharing. However, we still do not have a detailed understanding of which technologies are preferred and what challenges people still face when sharing information with them.

To address this problem, this thesis reports on a mixed-method study that explores technology preferences and health information sharing routines of distributed families coping with a chronic illness. The aim of these studies was to explore the nuances of technology selection and usage in such situations. The findings illustrate the reasons why people choose certain technologies over others, the ways in which they use them, and the challenges they face. Findings also point to the need for tools that mediate sharing health information across distance and age gaps, with consideration to respecting patient privacy and supportive roles while sharing such information.

Keywords: Domestic Computing; Health Informatics; Family Communication; Personal Health; Technology; Social Support
Dedication

This thesis is dedicated to my Mom and Dad. Your unconditional love and support over the years has moved me forward in life, encouraging me to always work towards my dreams. I am truly thankful to have you as my parents.
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Publications

Materials, ideas, and figures from this thesis have appeared previously in the following publications.


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1. Introduction

Sarah received a phone call from her sister; she was calling from the hospital with news that her 4-year-old daughter, Lisa, was just diagnosed with cancer. For five minutes, in silence, the two sisters shared their tears. Finally, voice cracking with emotion, Sarah’s sister described the diagnosis, the stage of cancer, Lisa’s planned treatment cycle, and possible success rates. Meanwhile, Sarah sat still, shocked and helpless. Still absorbing the news, she couldn’t make sense of the flood of information. She wanted to help in any way, but wasn’t quite sure how. No words could ease their pain at this moment. Sarah wished she could be there to hold them both, but there was 4,000 km between them.

Over the next six months, Lisa and her family were faced with many challenges. A great deal of these challenges focused on how people became aware of Lisa’s situation, her health status, and treatments. Not only did Lisa’s mom need to care for her, she also had to regularly share information about Lisa’s condition. People were concerned about Lisa, wanted to provide her with support, and simply wanted to feel close to her.

This is a common situation for many families who are faced with the challenges of coping with the diagnosis and treatment of a chronic illness. My research focuses on the latter part of the scenario, where I seek to understand the challenges users encounter with technological tools when trying to communicate with family members and patients coping with chronic illnesses.

To set the scene, I begin this chapter with an overview of family communication practices, including the concept of interpersonal awareness and social support within family networks. I then provide a brief overview of chronic illnesses and the importance of supporting the care of patients coping with such illnesses using personal health information management tools. Finally, I focus on technology preferences and routines of sharing personal health information across distributed families and present my research problems in this thesis. I conclude with my methodological approach used to address my research problems, followed by an organizational overview of chapters in the thesis.
1.1. Background

Most family members want to stay aware of each other’s activities on an ongoing basis to maintain a sense of connectedness. Neustaedter et al. (2013) describe connectedness as the ability for families to communicate with each other to coordinate, share experiences, and feel closer to one another. The term interpersonal awareness has been used in prior work to describe the information that people share to feel connected and how it is acquired and used between individuals with established relationships, where all have a real need and desire to know about each other (Neustaedter et al., 2006). This research shows that people share distinctive amounts of information about their lives with different people, creating several social groupings (Neustaedter et al., 2006).

Studies on the topic of distributed family relationships and how they are mediated by technology also help provide an understanding of current challenges and practices of family communication over time zones (Cao et al., 2010). The design of family communication tools to promote connectedness between remote family members relies on technologies that maintain degrees of awareness and privacy to navigate time differences and availability of family members (Cao et al., 2010). Existing awareness systems for domestic environments have sought to connect distributed households and mobile family members (Hindus et al., 2001, Mynatt et al., 2001, Romero et al., 2007). The influence of such systems on family communication practices is important in understanding the frequency in which family members wish to connect with one another.

Within the area of family communication, my research focuses on how health information is shared within health-specific situations. The Public Health Agency of Canada releases an annual report that evaluates the current status of specific chronic illnesses impacting the Canadian population. The Canadian Cancer Society estimates that 500 Canadians are diagnosed with cancer every day (Canadian Cancer Statistics, 2012). Other chronic illnesses, such as heart disease, diabetes, and musculoskeletal diseases continue to affect the aging Canadian population. Estimates suggest that 1.6 million Canadians have heart disease (Public Health Agency of Canada, 2009) and that the number of Canadians living with diabetes will reach 3.7 million by 2018 (Public Health Agency of Canada, 2011). Musculoskeletal diseases, such as arthritis and osteoporosis become debilitating over time, with approximately 7 million Canadians expected to be
affected by arthritis by 2031 (Public Health Agency of Canada, 2010) and an estimated 1.5 million Canadians (40 years of age or older) currently diagnosed with osteoporosis (Canadian Health Agency, 2009).

Rusk and Novey (1957) identified the impacts of chronic illnesses on families, citing that the effects will vary depending on socioeconomic factors such as age, family structure, economic circumstances, which family member is ill, and the resources of the family. During the diagnosis and treatment of a chronic illness, health information about the patient is often shared with family members such that they can stay aware of what is happening and also to provide social support.

Family members living in the same city have the opportunity to learn about the patient’s condition in person; however, geographically-distributed family members often must rely on computer-mediated communication tools to stay connected with the patient or rely on other family members who may provide updates. For example, a family member may hear about how the patient is doing during a phone call or someone may send out an email ‘update’. Hutchinson et al. (2003) suggest that computer technologies assist in keeping families in contact, but warn that the diversity of ages, skills, and interests should be accommodated in the design of such technologies. Technological preferences for communication in situations of a chronic illness face the same obstacles; for this reason it is important to understand which tools family members prefer when sharing health information and the reasons for their preferences (benefits), along with any implications in choosing to use them (costs).

Research outlining observations of caregivers (e.g., family members who directly support patients coping with chronic illnesses) specifically focused on the design requirements of personal health record (PHR) systems that consider the well-being of caregivers while assisting in coordinating their care of patients (Taylor et al., 2009). With the considerable amount of information work undertaken by patients and caregivers to learn about the disease, there exist a need for mobile health applications that consider the necessity (and urgency) for managing and sharing health information with family members (Klasnja et al., 2010). Reviewing research that examines how patients and their caregivers track and record personal health information and the tools they use to look up
and reference illness-related resources will provide a greater understanding of information practices during such trying times.

A variety of online tools have been created that focus specifically on health information sharing (e.g., LotsaHelpingHands, CaringBridge). Several companies have also created personal health record (PHR) systems that try to support the challenges of storing patient health information while providing patients with the flexibility of sharing their data with select individuals (Liu et al., 2011). This includes Google Health (Figure 1) and Microsoft HealthVault, recently licensed by Telus for Telus Health Space (Figure 2). While there exists a wealth of technologies that can be used for sharing health information when a family member has a chronic illness, there are few, if any, studies that provide a detailed understanding of how and why different technologies are used. The notable exception is work by Skeels (2010) that describes the technologies most commonly used for sharing health information; however, it does not explore the rationale behind such usage, the ways in which the various technologies are used, the specific benefits people receive from each, or the challenges that people face. Thus, we do not know where the tools might limit the activity of health information sharing.

Figure 1: Home page of Google Health system
1.2. Research Problems

This research explores the main problem that we do not have detailed knowledge that illustrates how to best design systems to facilitate the sharing of personal health information with distributed family members during the treatment of a chronic illness. Thus, we do not have a set of guidelines for understanding how to design such systems. To address this problem, I have divided it into three sub-problems. The first problem explores the design of existing and future systems to assist in personal health information management. The second problem explores technology preferences for sharing health information. The final problem explores the health information sharing routines of families amongst various social groups.

1. We do not have a detailed understanding of what features people desire in commercial systems to help manage and share personal health information within a family network. Commercial health information sharing systems contain a variety of features, such as the ability to search for information, the ability to share information with others, and the ability to maintain a journal online. Personal health systems can facilitate the management of health information; however, user concerns
with privacy controls, time commitment for data entry, and the inability for family members to provide emotional support, are known barriers to the adoption of such systems (Tang et al., 2005, Liu et al., 2011). Such features may be useful, however, it is unclear which are desired by family members to help manage and share information.

2. **We do not have a detailed understanding of what preferences people have for technology within the context of sharing health information.** Family communication in general has shown what technologies people prefer for communicating amongst family members, but we do not know how this applies to health-related situations (Grinter & Eldridge, 2001, Neustaedter et al., 2006). There exist many communication technologies, such as the telephone, video chat, email, and social media tools that have the potential to provide social support to patients coping with chronic illnesses (Skeels et al., 2010). While Skeels (2010) describes the technologies most commonly used for sharing health information, we do not understand the rationale behind such usage, the ways in which the various technologies are used, the specific benefits people receive from each, or the challenges that people face.

3. **We do not have a detailed understanding of what types of personal health information is shared, how the information is managed, and the problems family members face when communicating about such information.** Pratt et al. (2006) found that breast cancer patients have health information and records distributed in various forms, such as paper, email, and web references, but we do not understand how the information is managed. A number of studies have been conducted to understand the role that social networks play in supporting patients. Civan et al. (2009) defined roles within a patient’s social network whom they relied on to help with expertise sourcing. Skeels et al. (2010) studied the ways in which family members supported patients and their interactions within their social network. These particular studies defined important roles that family members and close friends typically adopt when helping a loved one cope with a chronic illness. However, the studies focused on the patients’ perspectives, and therefore exclude the family members’ perspectives. Such perspectives are important in understanding how loved
ones want to assist patients and in defining support roles and responsibilities within a social network.

1.3. Research Goals

My overarching objective for this thesis is to provide an understanding of family members’ needs for sharing health information and a set of design guidelines that informs the design of technological systems to support awareness and communication between family members coping with a chronic illness. To achieve this goal, I seek to address the following objectives, where each maps to a research problem as noted:

1. **Investigate what features family members want in health information sharing systems to support the sharing and management of personal health information in cases of chronic illness (Research Problem 1).** In Chapter 3, I conducted a two-part design study with 17 individuals from different households coping with a chronic illness, involving a paper-based task and design evaluation to investigate the design and functionality of existing health information sharing tools. Through a user-based evaluation of four web-based tools – two personal health record systems, and two health information sharing systems – we uncover desirable (and undesirable) features to better understand barriers that inhibit the adoption of such systems. Our results show that perceived trust with companies and good aesthetic design are important even when it comes to first impressions. Findings also suggest value in being able to share health status information with a core group of people while also being able to access information about the chronic illness.

2. **Investigate which types of technologies (synchronous vs. asynchronous) family members prefer to use for sharing health information in cases of chronic illness (Research Problem 2).** In Chapter 4, I conducted a quantitative study with the same sample, involving the evaluation of the most frequently used and accessible communication technologies. We selected two forms of synchronous technologies, the telephone and video chat, and two forms of asynchronous technologies, email and Facebook. Using the validated Affective Benefits and Costs of Communication Questionnaire (IJsselsteijn et al., 2009; Yarosh & Markopolous, 2010), our findings
demonstrated that regardless of physical distance between distributed family members, synchronous methods of communication afforded the opportunity to provide affective support while asynchronous methods of communication were deemed to be the least intrusive.

3. **Describe the communication routines of family members when sharing a patient’s personal health information in cases of chronic illness (Research Problem 3).** In Chapter 5, I conducted a two-part qualitative study with the same sample, involving a paper-based task and semi-structured interviews to record the composition of participants’ social networks with whom they shared information and their routines for sharing information about the health situation. My findings revealed that family members formed personal networks that were relatively close-knit and that younger generations within a family were often shielded from having a full awareness of the situation. Findings also more deeply explored how and why certain communication tools were used to share health information.

Together, by addressing these goals, I have come up with a set of design guidelines to inform the design of future systems that incorporate awareness and communication tools aimed at supporting distributed families coping with a chronic illness.

1.4. **Methodological Approach**

My research is focused on understanding health information sharing routines between family members and the technologies that support it. Figure 3 illustrates how this topic fits into the domain of human-computer interaction (HCI). The Association for Computing Machinery (ACM) defines HCI as “a discipline concerned with the design, evaluation and implementation of interactive computing systems for human use and with the study of major phenomena surrounding them” (Hewett et al., 2009). From a computing perspective, the entire experience between the human and the computer, including how information is presented to users and their interactions with such information and the computer falls within the umbrella of HCI. The interdisciplinary field of
HCI involves understanding who will use the interfaces, how they will use them, and ensuring they are effective for its purposes.

Figure 3: Context of research within domains of HCI and domestic computing

Creswell (2007) defines mixed methods research as one that collects, analyzes, and mixes qualitative and quantitative approaches in a single study or series of studies. My research uses quantitative data to statistically evaluate measured ratings of communication technologies and qualitative data to understand the context in which family members communicate. I employ a mixed-methods research approach to provide more comprehensive evidence to frame my design guidelines for future systems.

This thesis addresses design challenges of health information sharing technologies by understanding how to design systems that fit within people’s technology preferences and communication routines. To answer my research questions, I use findings from three different (design, quantitative, and qualitative) studies involving the same sample of 17 participants to understand the behaviours and effects that exist as part of a domestic network coping with a chronic illness. Though the three studies were conducted sequentially as part of one larger study (Figure 4), I describe it as three separate studies as the specific research focus and methodology employed for each was different.
The studies’ methodologies and findings are presented in this thesis in the order shown in Figure 4 to provide findings from a broader view (design study), narrowing in to a more detailed view (quantitative study), before finally focusing on the intricacies of health information sharing for chronic illnesses (qualitative study). However, in actuality, the studies were conducted in the following order: (1) qualitative study, (2) design study, and (3) quantitative study. Of course there is still a chance that completing all three studies in this order may have caused fatigue for the third study, and possibly the second study. However, due to the sensitive nature of the research area, we wanted to build rapport with the participants in order to make them feel comfortable enough to open up about their personal experiences and emotions. This was best achieved within a semi-structured format, where both the interviewer and participants had the opportunity to elaborate on the questions without being bound by study restrictions. While most participants were currently coping with a chronic illness in the family, others were reflecting back on a situation that happened several years earlier. The order in which the studies were conducted helped contextualize the situation to help participants better remember their experiences.

Bryman (2006) defines triangulation as the corroboration of quantitative and qualitative results from different methods. I purposely tried to triangulate the findings using three different research approaches to gain validity in similar findings revealed from each study.

Figure 4: Research study process
1.4.1. **Design Study**

My first research study sets out to understand the resources and tools family members wish to have in a health information sharing system. In this design study, I provided individual participants with a blank sheet of paper and asked them to draw an illustration that depicted any resources and tools they felt would be most beneficial in helping them in their role of supporting a family member who had a chronic illness. This design activity allowed us to get an understanding of the features that participants thought should be contained within a health information sharing system before they saw existing systems and might be biased by what they saw. The second part of the design study involved a summative evaluation of existing personal health record systems and health information sharing systems (Nielsen, 1993). Nielsen (1993) defines a summative evaluation as a usability test that assesses the overall quality of an interface. Our focus was not to compare the systems against each other; rather, our goal was to see what features participants would find valuable across a spectrum of systems. I describe the study findings in Chapter 3.

1.4.2. **Quantitative Study**

My second research study quantitatively compares the affective benefits and costs of synchronous and asynchronous communication tools during situations of chronic health illnesses. I conducted a within subject study using the validated Affective Benefits and Costs in Communication Questionnaire (IJsselsteijn et al., 2009, Yarosh & Markopoulos, 2010) where participants completed an online questionnaire comprised of 106 questions that evaluated how they communicated health information about the chronic illness with a family or friend living in a different household. I present the study findings in Chapter 4.

1.4.3. **Qualitative Study**

My third research study aims to understand the information shared about a patient’s health condition, health status, and the levels of privacy associated with each social grouping. An exploration into the requirements of patients, caregivers, and distributed family members included conducting semi-structured interviews to pose questions about participants’ current situations and to document the technologies used to
cope with the diagnosis. Schensul et al. (1999) note the benefits of semi-structured interviews, including the flexibility in which either the interviewer or interviewee can expand on an open-ended question. In this study, I posed questions to reveal with whom participants shared their health information with and what information was shared. Questions surrounding the location, mode, and frequency of their communication also provided an understanding of desired communication tools. I outline the study findings in Chapter 5.

1.5. Thesis Overview by Chapter

This section provides an overview of the research presented over the following seven chapters.

In Chapter 2, I start with a literature review of family communication practices. I begin with the motivation for this work, which is supporting family awareness using synchronous and asynchronous methods of communication. Next, I discuss personal health information management work, including unanchored work conducted by patients while on the go between home and medical centres. Following this, I identify explicit supportive roles within a social network. I conclude with a review of previously built awareness and commercial health information systems.

In Chapter 3, I discuss the methodology for the design study that included the evaluation of the design and functionality of four commercial health information systems to assist with the sharing of personal health information (Research Goal 1). I conclude the chapter with a clearer understanding of how new users react to health information sharing system features when they are presented in real commercially available products.

In Chapter 4, I discuss the methodology for the quantitative study that included a statistical analysis of affective communication benefits and costs for synchronous and asynchronous technologies (Research Goal 2). The study measures how family members rank two synchronous tools (telephone and video chat) and two asynchronous tools (email and Facebook) in their ability to express emotions, engage with others, provide a sense of presence despite being physically absent, and provide social support while mitigating feelings of obligations, unmet expectations and threats to privacy. I conclude
In Chapter 5, I discuss the methodology for the qualitative study that investigated family members’ communication routines and preferences for using each form of technology for health information sharing (Research Goal 3). I also describe the results which reveal the structure of ‘sharing’ networks, including groups of immediate family members, extended family, close friends, friends, and peers. Preferences for synchronous tools are further explored, along with a clearer understanding of concerns with video chat technologies.

In Chapter 6, I identify design implications for future systems to assist family members with secure health information sharing practices. This involves outlining communication needs and features of preferred technologies within smaller family networks while ensuring patient privacy and self-presentation and addressing concerns with trust.

In Chapter 7, I conclude this thesis by summarizing how I achieved my research goals. I also list my research contributions and suggest areas for future work in designing tools to support sharing health information between distributed family members.
2. Literature Review

In this chapter, I complete a literature review of family communication practices and systems that have been designed to support family awareness. I also include related work on health information management and sharing practices, and systems that have been designed to support such practices. My goal is to provide the reader with background knowledge on the communication routines family members adopt in situations with and without health concerns.

First, I explore how family members communicate using a variety of both synchronous and asynchronous technologies to maintain an awareness of domestic activities. Second, I summarize past studies that evaluate domestic awareness systems deployed to connect families living in different households. Third, I outline personal health information management practices, including how patients maintain personal health records within ‘unanchored’ settings. I follow this up with existing research on strategies patients use to share personal health information within their social networks, the direct focus of this thesis. I conclude with evaluations of existing electronic health record, personal health record and health information sharing systems in order to understand barriers to the adoption of such systems.

2.1. Family Communication

It is important to understand how families communicate in situations without health concerns. This provides an important foundation for comparing health situations to non-health situations. In this section, I talk about three aspects of family communication. First, I discuss the information that family members like to share and maintain an awareness of. Second, I describe the preferred uses of synchronous and asynchronous technologies. Third, I present research prototypes that have been developed to support family awareness.
2.1.1. **Family Awareness Information**

Studies have found that family members need to stay connected with each other and that immediate family members expressed an interest in maintaining an awareness of other family members' location, activities, and health status (Hindus et al., 2001, Neustaedter et al., 2006). Findings from Neustaedter et al.’s (2006) study involving a paper-based task and semi-structured interviews revealed three types of social groupings: home inhabitants, intimate socials, and extended socials. *Home inhabitants* included individuals who lived in the same household. *Intimate socials* included individuals who did not live in the same household but had a close relationship. *Extended socials* included individuals who did not live in the same household and maintained a more casual relationship. The study also revealed that the level of interpersonal awareness varied depending on the relationship. For example, *home inhabitants* typically required low-level, day-to-day details of social activities or work, while *intimate socials* sought details of future social activities spanning the next few days or weeks. While we see these social groupings exist for general family awareness and communication, we do not know how this applies to family awareness in situations where family members are communicating more frequently to share health-related information. Subsequent chapters build on the categories provided by Neustaedter et al. (2006).

Previous research has also focused on family communication for geographically-distributed members (Tee et al., 2009, Cao et al., 2010, Cao et al., 2013). Cao et al. (2010) evaluated challenges and routines surrounding family communication across distance. Time difference was indicated to be a key challenge for family members when choosing when to communicate, as usually there were misaligned schedules and narrow windows of communication available. Cao et al. (2010) suggest introducing tools that visualize the alignment of family members’ schedules to identify ideal communication times. Additionally, Cao et al. (2010) suggest addressing timely communication by capitalizing on the asynchronous nature of messaging and delaying delivery of messages to arrive at a suitable time for the recipient.

Tee et al. (2009) investigated the use of technology to support connectedness between extended families. Through interviews, their study found that while technology supported distributed relationships, it also enhanced feelings of obligation and burden.
when communicating with each other. They also found that synchronous communication tools, such as the telephone and video chat, were often preferred for emotional-based conversations. Findings suggest designing technologies that balance concerns people have when communicating, such as the perceived value of any interactions, the effort required, and the need to respect others’ privacy.

To understand current communication patterns within a family, Romero et al. (2007) conducted semi-structured interviews with three families and four additional individuals. Diaries were also kept by members of the three families, recording details about each communication and the after-effects of each, over the course of a week. Findings indicated that the most valued communications involved a clear, meaningful personal effort on behalf of the sender. The timing of these messages was also valued, meaning, that consideration should be given so as to not interrupt activities when a message was received; this supports the use of asynchronous awareness systems.

Evidently, prior research has sought to understand family awareness and communication practices involving family members who are either co-located or geographically distributed. My research extends the existing research to understand practices within the context of health information sharing, where the desire to stay aware of each other and communicate is even more critical.

### 2.1.2. Preferred Uses of Synchronous and Asynchronous Technologies

Studies have also evaluated a variety of technology preferences, revealing that people often choose tools that are most familiar to them and that they are most likely to reach the other person with (Grinter & Eldridge, 2001, Neustaedter et al., 2006). Neustaedter et al. (2006) found that a combination of synchronous (telephone, instant messaging) and asynchronous (email, text messaging) technologies were used by individuals to mediate challenges of distance separation. Heavy computer users also favoured email or instant messaging for information exchange (Neustaedter et al., 2006). Grinter and Palen (2002) studied the use of instant messaging amongst teenagers, including those who lived at home and those who lived away from home, and suggest its popularity is a result of increased autonomy, and affordance of creating a private space within a domestic environment. Grinter and Eldridge (2001) found that teenagers also
lean towards text messaging to arrange for times to talk, coordinate social meetings, and to chat due to its ease of use and affordability. Grinter et al. (2006) revisit their studies with a closer look at the use of text messaging and instant messaging as technological means to providing increased awareness and to coordinate inter-household communications.

Studies also show that people choose the richest medium when possible; thus video chat has been shown to support situations when people want to feel an additional connection with their remote loved ones, which can come from actually seeing a person (Walther & Parks, 2002, Judge & Neustaedter, 2010). Greenberg and Neustaedter (2013, 2012) evaluate the beneficial role a continuous video connection between long distance couples plays in supporting increased intimacy over distance. Judge et al. (2013) also evaluate how remote family members stay connected when separated by distance with their two media spaces – The Family Window (Judge et al., 2010) and Family Portals (Judge et al., 2011). Using ‘always-on’ connections, these media spaces demonstrated value in incorporating messaging capabilities within awareness systems with video chat functionality; however, they suggested the need for future technologies to consider public and private messaging within a shared inter-family space. My research builds on these studies by investigating the reasons why video chat is not a frequently used communication tool for sharing health information and suggests ways in which such a technology should be integrated into a system to encourage its adoption and use to share health information.

2.1.3. Family Communication Prototypes

Research in the area of awareness has been ongoing since the 1980s and 1990s, in which Media Spaces sought to explore video and audio links between parties in office environments (Khan & Markopolous, 2009, Luff et al., 2009). Systems have been designed to help individuals maintain an awareness of friends or family and provide a sense of connectedness to their users. The Digital Family Portrait (Mynatt et al., 2001, Rowan & Mynatt, 2005) was an early concept of an awareness system for the home, displaying abstract visualizations representing the activity of an aging adult. The Intentional Presence Lamp (Hindus et al., 2001) is another awareness system that would light up to display a family member’s presence at home. Designed as a picture frame and
lamp, these devices blended seamlessly into the home environment, causing minimal disruption but providing useful data. While neither supported direct communication, each provided in-the-moment information about a remote loved one.

Tollmar and Persson (2002) also studied domestic communication with an ethnographic study involving three families (six households). The authors hypothesize that providing some form of continuous-on and asynchronous connectivity could enhance relationships and awareness between distributed family members. Their study evaluated the deployment of the 6th Sense, a light sculpture that measures (and reacts) to the amount of body movement close to the lamp. A lit sculpture would indicate the remote presence of a family member on either end. Findings suggest the need to design technologies that limit the sense of surveillance or intrusiveness.

In addition to Judge et al.’s (2013) media spaces, several systems have been built to facilitate two-way family communication. SPARCS (Figure 5) is a prototype designed to facilitate the sharing of photos and calendar information (Brush et al., 2008). With previous research supporting the idea that a small amount of information creates a sense of connection between people (Liechti et al., 2000, Kay et al., 2005, Romero et al., 2007), the prototype proposes sharing suggestions on a daily basis, including photos from past experiences and upcoming calendar events (Brush et al., 2008). Analysis of a five-week field trial with seven pairs of families found that most participants felt that the additional sharing and communication contributed to increased feelings of connectedness and did not indicate an increasing sense of obligation to communicate.

Figure 5: SPARCS prototype (Image copied from Brush et al., 2006)
HomeNote (Figure 6) was a prototype evaluated by five households in a field trial over a period of a month (Sellen et al., 2006). The prototype supported situated messaging within a domestic environment, where text messages could be sent, received, and displayed on a tablet device (Sellen et al., 2006). The study found that the ability to remotely broadcast messages provided awareness and reassurance to family members, and also afforded a space for emotional expression (Sellen et al., 2006). With the ability to scribble notes and graffiti, the design of the prototype also appealed to children, which suggests the idea for designing technological tools where all members of a family have their own designated space (Sellen et al., 2006).

Figure 6: HomeNote prototype (Image copied from Sellen et al., 2006)

messageProbe (Figure 7) and videoProbe (Figure 8) formed part of the interLiving Project’s study, whose goal was to design new technologies that supported communication across distributed, multi-generational families (Hutchinson et al., 2003). The two technology probes served to evaluate the synchronous and asynchronous sharing of written messages and photos between households. The messageProbe was deployed in three households over the course of six weeks and helped researchers uncover communication patterns and technology needs. Much of the posted messages
involved news updates and coordinating family activities, but they also served as a means of asking questions and reminders (Hutchinson et al., 2003). The videoProbe was deployed in two households and evaluated over the course of one summer. Preliminary observations revealed that family members shared playful photos and also took photos of messages as a form of communication (Hutchinson et al., 2003).

*Figure 7: messageProbe technology (Image copied from Hutchinson et al., 2003)*

*Figure 8: videoProbe technology (Image copied from Hutchinson et al., 2003)*
Studies of these systems further suggest the benefits of technology that supports both synchronous and asynchronous communication to maintain a sense of connection between households, while preserving a balance of privacy for both parties. While we know this for general communication amongst family members, we do not know how this translates to families sharing health information. We also refer to these previous studies to learn how prototype systems have been designed to consider privacy concerns and feelings of obligation within distributed family households.

In the next section, I more deeply delve into the design, deployment, and evaluation of the ASTRA awareness system (Romero et al., 2007). I focus on this particular system as the evaluation methods are similar to what I use in my studies.

2.1.4. The ASTRA System

Romero et al. (2007) completed a three-part study that saw the evaluation of family communication patterns and the resulting feelings of connectedness and social presence, using the Affective Benefits and Costs of Communication Questionnaire (ABC-Q). The questionnaire focused on affective benefits and affective costs of communication. Affective benefits referred to four categories: emotional expressiveness, engagement, presence-in-absence, and social support. Affective costs referred to three categories: obligations, unmet expectations, and threats to privacy for communication (IJsselsteijn et al., 2009, Yarosh & Markopolous, 2010). The findings from this qualitative study guided the design of the ASTRA awareness system, which was then tested by families, first in a laboratory environment, followed by a field trial (Markopoulos et al., 2004).

The ASTRA awareness system concept was designed so as to achieve high levels of connectedness while minimizing affective costs (Romero et al., 2007). System features included the ability for users to capture and send pictures with handwritten notes in an asynchronous way (Figure 9). Users would use a mobile device to take a picture, write a note, and then send it to a tablet device at home, which was equipped with a touchscreen interface that allowed family members to browse messages or check the availability of others that were connected to the system (Romero et al., 2007).
The initial evaluation of the ASTRA system was conducted in a laboratory environment; however, the findings from the trial prompted for a more extensive field trial by families in their homes. Interviews and diaries recorded four families’ (two pairs) communication patterns one week before the system was equipped in their homes, and one week after. The results from the field trial indicated that the ASTRA system helped distributed families stay in touch with each other by providing opportunities of awareness, connectedness and sharing experiences. While motivating to see results that appear to point to the adoption and acceptance of an awareness system within the home, it would be interesting to record the ongoing use of the system. Findings from a one-week trial can also be skewed by the novelty of the device and the requirement to use the system over a set period, knowing that data would be recorded for research purposes.

Now that we have a solid understanding of family communication practices in everyday situations, we turn our attention to communication practices within chronic health situations, which is the focus of my research. I begin with an overview of personal health information management routines to provide an understanding of the volume of information that is involved in such situations. I follow this with details of existing systems, both personal health record systems, and health information sharing systems, to outline how past work has sought to address the sharing of personal health information across family networks.
2.2. Personal Health Information Management

With a new diagnosis, patients will likely adopt new personal health information management (PHIM) practices to accommodate requirements that come with the treatment of a serious illness. Such practices include tracking personal medical data, coordinating medical appointments with day-to-day activities, managing treatment cycles of medication and maintaining a record of individual clinician details (Pratt et al., 2006, Huh & Ackerman, 2012). Patients accumulate an overwhelming amount of information throughout their care, and the management of this information must be integrated with patients’ personal and professional lives. Several studies have been conducted to understand how cancer patients manage health information. I articulate these in the next section.

2.2.1. Defining Health Information Work

Pratt et al. (2006) studied seven breast cancer patients to understand their PHIM needs during their treatment. Findings from the study demonstrated that information is distributed in various forms, such as paper, email, and web references; however, people did not necessarily know what to do with all the information they received, often forgetting to use it or becoming overwhelmed because of the language and volume (Pratt et al., 2006). Participants also expressed the desire to share certain details of their health information with others, but were frustrated with the limitations in information exchange, such as calls with insurance companies or clinicians, which might often occur in ‘semi-public work settings’.

Cancer patients identified three overall challenges in managing information related to their health care. First, patients had the need to integrate personal, professional, and health-related information into a centralized location, such as appointments, prescriptions, web pages, medical bills, and medical insurance information (Pratt et al., 2006). Second, patients sought to group related information in an accessible manner that would assist in health-related decision-making (Pratt et al., 2006). Third, patients expressed an interest in the ability to share information with individuals in various social groupings of their network (Pratt et al., 2006).
While the study clearly outlined these dominant challenges that breast cancer patients faced, questions remain as to the diverse PHIM needs of patients suffering from other chronic illnesses. My research builds on this study by investigating such needs of patients coping from chronic illnesses such as heart disease, diabetes, and musculoskeletal diseases. The researchers also did not include any design implications, leaving room to extend the study further to recommend tools that would address the challenges patients face when adopting new information management practices. I outline design implications from my studies in Chapter 6.

2.2.2. **Defining Unanchored Health Information Work**

While much research has explored personal health record (PHR) systems and PHIM practices, little work has been done to understand information practices by patients when away from a computer, which happens often as patients spend time at hospitals and travelling to and from appointments. Klasnja et al. (2010) describe ‘unanchored work’ as activities patients do without access to common informational and physical resources, such as a patient remembering to ask her doctor about treatment side effects while away from her computer. Little work has been done to design technologies to support such unanchored work as patients spend time travelling to and from appointments.

Klasnja et al. (2010) focused their study on such unanchored health information work, defining common unanchored activities, its causes, and workarounds adopted by breast cancer patients. Findings from the study identified two streams of unanchored work that often occurred while patients were away from home or their work areas: *information capture* and *information retrieval*. Examples of *information capture* included tracking symptoms and side effects, collecting information for upcoming appointments, recording clinicians’ explanations and advice, and capturing information in unexpected situations. Examples of *information retrieval* included planning and scheduling treatments and retrieving health information at a clinic (Klasnja et al., 2010).

Understanding the main causes of unanchored work can assist in designing technologies suited for such scenarios. For example, Klasnja et al. (2010) note that participants may suffer from side effects of treatments, making it difficult for them to remember information presented to them during appointments (*diminished attention*).
Participants also require assistance in preparing for appointments and would benefit from having information readily available to answer questions about medication, doses, and medical history from memory (lack of familiarity) (Klasnja et al., 2010). Mobile tools can assist participants who think about questions for their doctors when they were away from their computers, like at work, or in the car, or have to schedule appointments after a series of phone tag with clinics (necessity for mobility) (Klasnja et al., 2010). Critical information encounters also happened during clinical appointments where participants lacked technical resources like Internet connections, computers or printers (inadequate work environments) (Klasnja et al., 2010).

A common strategy adopted by patients to address this unanchored information work included mobile information collections, either assembled appointment bundles (lists of questions, articles to discuss, bottles of medications, books, crossword puzzles, DVD players to pass time), mobile reference collections (pocket calendars with business cards) or simply carrying “everything” (Klasnja et al., 2010). Patients sometimes would write notes down as needed (post-its, notebooks, etc.) and reconcile it before an upcoming appointment or ask someone to accompany them to the appointment (Klasnja et al., 2010).

The researchers suggest design recommendations to support unanchored patient work, including mobile tools that allow searching and that facilitate the easy capture of a range of more informal information, such as questions, notes, and to-do lists. While it is likely that much of the health information work overlaps, patients being treated for other illnesses, such as degenerative health conditions, may not have similar needs or abilities. The findings also do not consider any unanchored work done by any caregivers who likely have a supportive role in the medical treatment of the patients. Therefore, it is still unknown how unanchored work of family members overlap or integrate with that of patients. This is an important area I explore as patients often lean towards family members for social support, including emotional support or assistance with routine domestic tasks. In the next section, I explore the support roles within a patient’s network.
2.3. Social Support

The importance of human connectedness is especially critical during such times of a health crisis as patients may undergo a painful recovery process and seek support from their loved ones who may be co-located or distributed in different cities. Patients may also face decisions surrounding the granularity of information to share and with which social groups (e.g., immediate family members, friends, co-workers) to share it with, choosing certain methods of communication to disseminate the information accordingly.

2.3.1. Identifying Explicit Roles within a Social Network

A number of studies have been conducted to understand the role social networks have in supporting patients. Social networks are most effective when kept up to date on the patient’s status, yet updating everyone takes effort that patients cannot always put in (Newman et al., 2011). Civan et al. (2009) recognize that coping with a new health issue often requires individuals to acquire knowledge and skills to manage personal health. In this study, researchers aimed to identify ways in which patients sought expertise within their networks. Findings reported that a common concern expressed by participants included the need to be especially careful not to burden family or friends with their health issues, only identifying select individuals in their social network whom they would rely on to help with sourcing expertise as it relates to their condition: gatekeepers. Gatekeeper roles were broken into three variations: conduit, contact broker, and champion.

A conduit was responsible for funnelling information to the participant and acting as a point of contact to pass messages from the patient to an external source (Civan et al., 2009). A contact broker would introduce participants to sources of expertise outside the support community, acting more as a referral (Civan et al., 2009). A champion was often a key source of expertise with a breadth of knowledge that crossed multiple domains (e.g., breast cancer survivor and a registered nurse) (Civan et al., 2009).

Skeels et al. (2011) also noted the reliance of sharing personal health information with various social groups while maintaining personal privacy, identifying two roles within a system that could support breast cancer patients: proxy and coordinator. A proxy is someone patients trust to interact with their social network on their behalf, including
setting up a profile, inviting people to a helping network, and deflecting unwanted offers of help. A coordinator is someone who manages one piece of the support network, and is expected to have a limited scope of access to information. Expertise related to breast cancer was also sought through others who shared the same experience (e.g., breast cancer survivor). Because of the variability among diagnoses, patients sometimes sought advice from those who shared a cancer diagnosis, often finding comfort in discussing treatment options and side effects.

These particular studies defined important roles that family members and close friends typically adopt when helping a loved one cope with a chronic illness. However, since these studies involved breast cancer patients, a gap in these studies that I tackle in my research is to understand the perspectives of family members and friends of patients. Broadening the sample pool to be more representative of a true social network would contribute generalizable findings applicable across more diverse networks. This therefore excludes a unique perspective and presents an opportunity for my research to extend. This perspective is especially important in understanding how loved ones want to assist patients and in defining support roles and responsibilities within a social network. In Chapter 5, I explore these roles further.

2.3.2. Maintaining Self-Presentation within a Social Network

Online health communities (OHC) and social networks, such as Facebook user groups, provide emotional support and resources for patients as they seek information online. Newman et al. (2011) studied with whom and how people shared different types of information as they pursued social goals related to their personal health. Conducting semi-structured interviews over the phone with 14 adults (3 male and 11 female of unknown ages) who were members of an online health community and Facebook, researchers studied how Facebook and OHC provided emotional support, motivation, accountability and advice in relation to weight loss and diabetes management.

Findings included identifying who and how people shared information related to health, challenges faced in building and accessing a support network, and impression management (managing self-presentation through status updates and information posted on a profile) while pursuing health goals (Newman et al., 2011). It was observed that not
all participants resorted to online communities for emotional support, preferring the physical presence and face-to-face interactions to discuss personal struggles rather than online postings. The reservations with posting to OHCs existed in concerns with maintaining a positive support group. Some participants avoided people who would bring them down, and these were usually people who shared frustrations and negative feelings too often.

The concept of impression management is important in the area of health information sharing as it sheds light on how chronically ill patients behave to manage their impressions within their social context. Patients may require help with everyday duties while managing the ongoing treatment of their illness and coping with the emotional impacts of the diagnosis. Yet, patients may deliberately conceal their true health status by hesitating to reach out to their support network so as not to impose a burden on family or friends. Benjamin et al. (2012) observed a similar pattern in their study of how seniors with chronic pain carefully managed their interactions with others to maintain a certain level of self-presentation. Participants in their study were selective about what information was revealed about their condition, sometimes concealing their experiences with pain in order to 'preserve face' and 'maintain positive impressions'. Again, my research explores the perspectives of family members and how they are considerate of patients’ concerns with becoming a burden on their loved ones.

Newman et al. (2011) suggest design implications, including greater and easier creation of custom groups for specific communication patterns to address the ‘who’ to share with. However, the idea of reorganizing network groups is not a new idea, as evidenced in popular social network grouping capabilities (Facebook ‘lists’ and Google+ ‘circles’); the authors, who propose streamlining the process of creating these groups, recognize this. Newman et al. (2011) also suggests an opportunity to provide coaching (on effective communication) as a support mechanism to both those who share and receive health status updates. This is a difficult solution to implement as I foresee a challenge in coaching all users of OHCs. Instead, a design opportunity I see stemming from this study could be smart intelligence cues that learn from user posts and provide some type of feedback that guides users on posting motivational messages. Another opportunity I see applying to the design of a health information sharing system would be to maintain a close-knit circle of family and friends and options to integrate access to select online
communities with whom patients could choose to connect with. My research explores who family members wish to share information with to better design social groupings within the context of health information sharing. This is described in Chapter 5.

The next section discusses the variety of health information management systems that have been designed to assist patients and family members with the management and sharing of patient data.

2.4. Health Information Management Systems

Studies have sought to elicit requirements of technologies to mediate the impacts of an illness on patients, caregivers, and family members (Hassling et al., 2005, Hawkey et al., 2005, Mallinger et al., 2006, Taylor et al., 2009). With a clearer understanding of the types of personal health information management practices, we now turn our focus to systems that have been developed to assist patients and their families. Here, we explore the challenges people have faced in the adoption and usage of existing systems. This includes electronic health records, personal health records, and health information sharing systems.

2.4.1. Electronic Health Record Systems

Patient electronic health records can be complex. Prior work has been undertaken to design appropriate visualization and navigation techniques to help explore such complex records (Plaisant et al., 1996, Bui et al., 2007, Hallett, 2007, Wang et al., 2008). From the perspective of maintaining awareness of patient care, as this increasing amount of health data accrues in a patient’s record, the current methods of compiling and organizing such data does not support the cognitive processes of family members; therefore visualizing patient medical records becomes imperative in assisting families as they try to interpret the chain of events and provide support as patients cope with symptoms and treatments (Plaisant et al., 1996).

Previous work has produced systems, including Lifelines, Lifelines2, CLEF Visual Navigator, KNAVE II, and TimeLine, which all use timelines to help with the exploration of abstracted health information. Lifelines depict multiple facets of personal patient medical
records within one screen (Plaisant et al., 1996). The system represents linear time using horizontal bars, corresponding to our natural perception of time as an ordered collection of temporal events proceeding from the past to the future. However, it fails to provide visual cues and the lack of gridlines and poor choice of colors make it challenging to decipher exact dates.

Lifelines2 (Figure 10) extends Lifelines by allowing the comparative analysis of multiple patient medical records at a time (Wang et al., 2008). Interactive features of Lifelines2 include the ability to align, rank and filter, allowing users to easily spot co-occurring and neighbouring events. With a simple dropdown menu, users can easily align multiple patient records by a particular event, rank the records by particular details, and further filter to reorder and narrow the set of records.

![Figure 10: Lifelines2 main window depicting temporal summaries of health information (Image copied from Wang et al., 2008)](image)
CLEF Visual Navigator provides navigation tools to browse medical histories and generates textual summaries (Hallett, 2008). Employing three parallel timelines, the system plots the patient’s medical events according to diagnosis, treatments, and investigations. Color and gridlines are also effectively used to help cue users to the individual sections.

KNAVE II enables visual exploration of a network of links (Goren-Bar et al., 2004). The provision of a folder structure allows users to form drill down to a particular level of detail. Additional exploratory tools include icons that enable users to perform actions such as re-aligning panels, adding/removing statistics, and left and right arrows to skip to periods in the past or future. As can be seen in Figure 11, this electronic health record system contains panels in which navigating the folder structure displays the relevant health data. Each panel also has time-sensitive zoom functionality that allows a user to select a specific predefined period of time.

Figure 11: KNAVE II main window with data panels (Image copied from Wang et al., 2008)
TimeLine represents a visualization of patient records reorganized around medical diseases and conditions (Bui et al., 2007). Personal patient details and health conditions are presented at the highest hierarchical position of the screen – the top left corner. The systems also incorporate temporal navigation tools such as expanding/collapsing rows and sliders for selecting a particular time period.

These electronic health record systems were designed with the intent to provide physicians with visualizations of health data that can be used to provide patient care, including the potential to use clinical data from multiple patients for research purposes. The challenges though, exist in the limited available research methods to work with large data sets, resulting in difficulties inferring meaning from data; information visualization can help mitigate such challenges by aggregating data and surfacing any patterns that may be hidden. Interaction with data via direct manipulation is absolutely critical for the analysis process; this can be achieved with navigational and zooming functionalities that enable users to filter specific information to help infer meaning behind such large datasets (Plaisant et al., 1996, Plaisant et al., 2003).

Understanding the challenges of displaying patient data in a usable interface is important in designing systems to store such data. As the potential users of such systems can include family members, patients, and medical professionals, we need to understand how such data can be presented in a usable manner. I explore this in Chapter 3.

2.4.2. Personal Health Record Systems

Personal health record (PHR) systems capture health data entered by individuals and assist patients with managing the care of their illnesses (Tang et al., 2005). Systems provide tools to encourage patients to have a more active role in the care of their illness, including decision-support capabilities and information storage (Tang et al., 2005). Previous work has mainly focused on the usability and utility of personal health record (PHR) systems (Tang et al., 2005, Halamka et al., 2008, Peters et al., 2009).

Project HealthDesign seeks to stimulate development of new personal health management tools by combining the content of personal health records and data tracking tools to create a set of prototypes that can easily be used by individuals to achieve personal health goals (Brennan et al., 2007). In their paper, Tang et al. (2005) summarize
discussions from a 2005 Symposium of the American College of Medical Informatics and suggest that the integration of EHR systems with PHR systems would help patients become active participants in their care. The authors cite ‘education’ as a means to overcome barriers to the adoption of PHR (Tang et al., 2005). In addition to educating medical schools on the use of EHRs and PHRs, developers of such systems should consider advanced topics related to privacy, security, and authentication to address user concerns with privacy and data management (Tang et al., 2005).

Liu et al. (2011) extend work by Tang et al. (2005) by evaluating the use of PHR systems by multiple stakeholders to understand the challenges limiting their use. This included end-user evaluations, interviews with clinicians, and heuristic evaluations of three systems, Google Health, Microsoft HealthVault and WorldMedCard. Findings reported that many end users found the PHR systems were too complicated to use, yet clinicians thought they were over-simplified. Extensive functionality was also seen as being problematic as patients would only use a subset of features. End users expressed the need for medical jargon to be simplified from complex terminology to easy, everyday language they could relate to. A clear barrier to the adoption of PHR systems was the need to secure records and provide appropriate access controls to ensure privacy; however, they reported that such security controls should be integrated into the system in a way that was intuitive and easy for users.

As part of her background research, Skeels (2010) identified key functionalities found in existing technologies. Microsoft HealthVault was shown to be focused on the management of health information while LotsaHelpingHands targeted the social aspect of healthcare, with tools that support collaboration, photo sharing, and the ability to share background information and resources (Skeels, 2010). While this categorization is valuable, these systems were not evaluated to understand user reactions to them. Chapter 3 presents such an evaluation.

2.4.3. **Health Information Sharing Systems**

Targeted for use by chronically ill people, Sunyaev and Chornyi (2012) implemented a health management prototype that integrates with PHR platforms, Microsoft HealthVault and Google Health. Named the Health Management System, the
tool was a cloud-based, secure application designed to assist patients with self-management of diabetes and data exchange. The study was successful in testing the technical feasibility of integrating PHR application programming interfaces (APIs).

Hartzler et al. (2011) studied the granular sharing of personal health information using the HealthWeaver system. HealthWeaver is a web-based tool designed to support information management needs of cancer patients. It enables patients to create, manage and share health information with select members of their social network. Features of the system included the ability to track one’s health; request help from someone; upload documents; create notes, lists, blog posts, web bookmarks and calendar events; and, share select items with a social network. Researchers conducted a lab study of 20 cancer patients and survivors to investigate granular sharing controls of the HealthWeaver interface. During their evaluations, Hartzler et al. (2011) found that a clear barrier to the adoption of their system was the need to secure records and provide appropriate access controls to ensure privacy; however, they argued that such security controls should be integrated into a system in a way that was intuitive and easy for users.

Based on interviews, Consolvo et al. (2004) also sought to understand the type of information shared, the type of care provided, and the roles of individuals involved in the care of a patient. Using the CareNet Display as a technology probe, participants of the study were able to access specific events about a remote family member, such as meals, medications, moods, and a calendar. Findings of the study included details of care networks, separated into three categories based on the impact in providing care: drastic life changes, significant contributions, and peripheral involvement. The authors also presented guidelines for health information systems focused on supporting the well-being of elderly patients. These included ensuring privacy for network members, reducing cognitive load, and minimizing issues of trust.

Understanding desirable (and undesirable) features of existing awareness, EHR, PHR, and HIS systems will help inform the future design of technologies that will support patients and family members, who are simultaneously impacted with the diagnosis and treatment of a chronic illness. My work builds on these studies by evaluating the first impressions of end users for key functionalities in existing health information sharing systems; this is discussed in Chapter 3.
2.5. Summary

In this literature review, I have focused on the exploration of four areas in the domestic space. First, I explored family communication routines within non-health related situations, including preferred uses of synchronous and asynchronous technologies. Here, I show that people use a variety of tools to communicate with each other, and the use of such tools vary depending on the purpose of connecting with each other. I then describe a number of awareness systems evaluated in domestic environments to understand how distributed family members stayed connected. The amount of prior work in this field demonstrates the desire for systems to provide distributed families with ways to stay aware of each other. My work builds on this prior work by evaluating awareness needs for distributed families coping with a chronic illness. Third, I reviewed existing research on strategies patients use to share personal health information within their social networks. I compare roles defined by previous studies and describe three roles individuals adopt within a patient’s network, either co-located or remote, to support the patient. Next, I outlined an overview of three types of systems designed to help manage patient data: electronic health records, personal health records, and health information sharing. Such systems are demonstrated to be desirable if they are relatively simple to use and incorporate privacy controls to secure patient data.

In the remaining chapters of this thesis, I will draw on the literature reviewed in this chapter to investigate technology preferences and routines for sharing health information within a family network. The next chapter describes the results of our design study that focused on evaluating existing commercial health information sharing systems.
3. Evaluating Commercial Health Information Systems

A variety of systems, including electronic health record systems, personal health record systems, and health information sharing systems, have been created to help people manage their personal health information. In this chapter, I look at the adoption of such systems by reporting on the findings from my first study that had participants complete two qualitative activities: a design activity and summative evaluations. The goal of this study was to investigate what features family members wanted in health information sharing systems to support the private sharing and management of personal health information in cases of chronic illness (Research Goal 1). More specifically, this means understanding how users react to searching functionality, social network integration, and information management.

The results from this study are described as follows. First, I document the various features participants desired within a health information sharing system. Second, I outline user reactions to four web-based tools – two personal health record systems, and two health information sharing systems.

3.1. Methodology

Nielsen (1993) describes a summative evaluation as a systematic inspection of a user interface design to assess its usability. We conducted a design study where we had our sample of 17 individuals participate in a design activity, followed by evaluations of the design of existing health information sharing systems. The goal was to draw out design guidelines and to more deeply explore what tools and information people desired in health information sharing systems (Research Goal 1).
3.1.1. **Participants**

To represent the broad scope of a family network, we purposely sampled participants diverse in age, education, profession, and illness. Creswell (2007) defines this strategy of purposeful sampling as the means for a researcher to select individuals for a study because they can assist in understanding the research problem. Individuals who replied to the study’s recruitment poster (Appendix A) were sent a qualifier email (Appendix B) asking the following questions to ensure their experiences were relevant to the study’s research problem:

- Please identify the chronic illness the family is coping/has coped with.
- When was the illness diagnosed?
- Which city do you live in?
- Where does the patient live?
- Where do your family members live?
- Do you share or receive any health information related to the patient?
- What is your relationship to the patient?

Seventeen individuals (4 males, 13 females) were recruited using advertisements on social media sites, postings on an online public community, and with a solicitation to students at a local university. Participants were distributed between the ages of 21 and 61; five were between 20-29, seven between 30-39, three between 40-49, one in their 50s, and one in their 60s. Table 1 provides an overview of our participants’ demographics, including the year in which the family member was diagnosed, the illness the family was coping with, and the role the participant assumed during the health situation. It also outlines participants’ uses of the four communication tools to share health information. Here, we can see that all participants used the telephone and email interchangeably to share health information; video chat was used less frequently; Facebook was only used by approximately 50% of participants, with four of them specifically only using the instant messaging (IM) feature within Facebook to communicate. Participants were diverse in their socioeconomic status with professions falling in academic and public sector industries.
<table>
<thead>
<tr>
<th>AGE</th>
<th>GENDER</th>
<th>DIAGNOSIS</th>
<th>ILLNESS</th>
<th>ROLE</th>
<th>PHONE</th>
<th>EMAIL</th>
<th>VIDEO</th>
<th>CHAT</th>
<th>FACEBOOK</th>
</tr>
</thead>
<tbody>
<tr>
<td>28</td>
<td>F</td>
<td>2011</td>
<td>Degenerative</td>
<td>Local Supporter</td>
<td>•</td>
<td>•</td>
<td></td>
<td>•</td>
<td></td>
</tr>
<tr>
<td>39</td>
<td>F</td>
<td>2009</td>
<td>Degenerative</td>
<td>Local Supporter</td>
<td>•</td>
<td>•</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>31</td>
<td>M</td>
<td>2010</td>
<td>Cancer</td>
<td>Caregiver</td>
<td>•</td>
<td>•</td>
<td>•</td>
<td></td>
<td></td>
</tr>
<tr>
<td>54</td>
<td>F</td>
<td>2006</td>
<td>Lung Disease</td>
<td>Local Supporter</td>
<td>•</td>
<td>•</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>29</td>
<td>F</td>
<td>2008</td>
<td>Diabetes</td>
<td>Local Supporter</td>
<td>•</td>
<td>•</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| 32  | F      | 2006      | Cancer     | Local Supporter | • | • | • | • | IM
| 61  | F      | 2006      | Degenerative | Local Supporter | • | • | • | • | IM
| 21  | F      | 2011      | Diabetes   | Remote Supporter | • | • | • | | |
| 30  | F      | 2007      | Heart Disease | Remote Supporter | • | • | | | |
| 31  | M      | 2008      | Cancer     | Caregiver      | • | • | • | | |
| 44  | M      | 2009      | Cancer     | Caregiver      | • | • | | | |
| 37  | F      | 2006      | Degenerative | Remote Supporter | • | • | | • | IM
| 44  | M      | 2009      | Cancer     | Remote Supporter | • | • | • | • | IM
| 26  | F      | 2011      | Lung Disease | Local Supporter | • | • | | | |
| 42  | F      | 2008      | Heart Disease | Remote Supporter | • | • | | | |
| 25  | F      | 2007      | Cancer     | Remote Supporter | • | • | | | |
| 35  | F      | 2010      | Cancer     | Caregiver      | • | • | • | | |

Table 1: Overview of participant demographics, illnesses, roles, and technology use for health information sharing

All participants had experience with basic technology, such as the telephone and computer, and online communication, such as email and Facebook. These technology preferences are further explored in subsequent chapters. All participants resided in North America and their family members were located globally, living in North America, Europe, Asia, and Australia. Participants had an immediate family member (e.g., child, sibling, parent) who had suffered from a chronic illness within the past five years or was currently suffering with an illness. Illnesses included various forms of cancer, diabetes, leukemia, Alzheimer’s disease, and multiple sclerosis, as they all often require ongoing treatment over an extended period of time and typically involve regular communication between family members.

3.1.2. Design Activity

In the first stage of the study, we provided individual participants with a blank sheet of paper and asked them to draw an illustration that depicted any resources and tools they felt would be most beneficial in helping them in their role of supporting a family member who had a chronic illness. Figure 12 is an example of a participant’s ideas generated during the design activity. In her sketch, we see news and updates about the patient’s situation at the top, along with information about the illness. This is followed by
the need to maintain a high-level view of the treatment stages and resources for the illness with a timeline at the bottom. Overall, the design activity allowed us to get an understanding of the features that participants thought should be contained within a health information sharing system before they saw existing systems and might be biased by what they saw.

Figure 12: P9's design of resources needed to help with the treatment of lung disease

Figure 13 is another example of a participant’s ideas generated during the design activity. In his sketch, we see the need for a place to broadcast news and health updates about the patient. In addition to an area for photos, we see the desire for access to maintain (and share) a high-level timeline of the treatment stages and resources for the illness.
Figure 13: P3's ideas of tools to support sharing health information
3.1.3. **Summative Evaluation**

The second part of the design study involved a user evaluation of existing systems. We presented each participant with images of the screens from four systems and asked them to talk out loud about the system. By selecting these systems, we were able to provide a broad range of features that participants could evaluate beyond just tracking data, which was previously studied by Liu et al. (2011). For each system, we selected one or two screens that represented the sites’ core functionality. Some systems needed only one image to do this, while others sometimes required two because functionality was spread across multiple pages.

We chose to show images as opposed to having the participant look at the actual site. This was because sites often required user accounts to be created and an initial setup of information within the site before more typical usage could occur. Such activities would be time consuming within a study of new users and, if performed prior to the study, it would have made it so we could not see participants’ first reactions to the sites. Our method was also beneficial as it allowed participants to directly mark on the images the features that they liked (using green) and/or disliked (using red).

Our goal was not necessarily to compare the systems (though sometimes this did occur during the study); instead, we wanted to see what features participants would find valuable across a spectrum of options.

1. **CaringBridge**: This system offers users narrative abilities to share personal stories and photos. We presented the profile and photo sharing pages. The profile page shares the personal story of the health illness and the photo sharing page provides an area to post photos and leave comments.
Figure 14: The journal page of CaringBridge
Figure 15: The photos screen of CaringBridge
2. **PatientsLikeMe**: This system provides users with access to information about illnesses and patient statistics. Users are able to share their health condition, treatments, and symptom information to track their own progress while helping others coping with the same illness. We showed images of the home page (Figure 16) and the illness details page (Figure 17). We also chose this site as it was unique from the others in its design. It does not have a standard menu bar along the top and directly asks the user three questions on the home page in order to begin their search for information related to an illness.

![Figure 16: Home page of PatientsLikeMe](image)
3. **Microsoft HealthVault**: This system enables users to track and manage their personal medical records. We showed an image of the home page (Figure 18) that displays all of the functionality supported, including the ability to track prescriptions and organize medical records. From this page, users can create an account, share with friends using social media, and learn more about industry partners.
Figure 18: Home page of Microsoft HealthVault
4. **LotsaHelpingHands**: Similar to CaringBridge, this system offers social supportive features for patients, caregivers, family members, and friends. A personal profile page provides a space for information about the patient and calendar options provides a means to assist with patient appointments and other tasks. We showed the site’s home page (Figure 19) that provides a lot of background information about the organization and its purpose.

![Figure 19: Home page of LotsaHelpingHands](image-url)

**Figure 19: Home page of LotsaHelpingHands**
Once participants reviewed the features for all the systems, we asked them to discuss the systems and their features based on their needs for supporting a family member coping with a chronic illness.

3.1.4. Analysis Methods

Study data was analyzed by reviewing each drawing from the design activity and compiling design evaluations for each of the four systems. Using open coding techniques (Strauss, 1998), codes were assigned to any recurrence of desired features (e.g., [F-ADDRESS] for contact information of medical facilities) and noted observations (e.g., [N-DONATION] for the disliked feature of donations, [Y-FORUM] for the liked feature of discussion forums). A comprehensive list of codes was then reviewed to understand their context (Appendix H). We centralized our focus on the core patterns found in our analysis.

The next section describes the results of this study, where I detail the various tools and system features family members sought to assist with the care of a chronically ill patient.

3.2. Results: Tools to Support Sharing of Health Information

My analysis of the design activity revealed several themes when it came to desired features for a health information sharing system. Again, to avoid potential bias, the data from participants' drawings was collected before participants saw the existing tools. First, when participants completed the design activity, several participants talked about wanting to be able to get more information about the chronic illness. This could be from family or friends, online resources, or even strangers online who had experience with the illness or were more familiar with symptoms and treatments.

“I haven’t [used discussion forums online]. I think it will get to the point where that will be helpful. The worse she becomes, the more information we want to get, both from people who are experiencing the same thing as well as family and friends, whereas it’s been more contained up until recently.” – P1, Female, Age 28
“Maybe something where I can get more information, like if there was a search engine where you can type in whatever the condition is and you can get more information about it. Like something where you can search for her condition.” – P8, Female, Age 21

Second, in the design activity, several participants talked about being able to see the patient either through photos or a video chat system like Skype. This suggests that family members value the suggested presence of an individual afforded through photos and a real-time video connection. Here participants wanted viewing to be targeted between two people, as opposed to posting images or videos online of the patient.

“It would be neat if we could have a web camera that I could set up so that others can actually see her, like on a weekly basis. And even if I had a camera so they could see how I was feeling in regards to our mother. I’d like to be able to talk to them in person, to be able to see them, and they can see my reaction.” – P7, Female, Age 61

However, while some participants sought a space to share photos, data from the design activity also revealed that the idea of sharing images of the patient more broadly with other family and friends received mixed reactions. About half of our participants saw it as an unnecessary feature. This suggests the need to consider varying degrees of privacy when sharing photos online.

“I don’t see the relevance for photos. It doesn’t have any importance. First of all, I don’t see myself doing this, or any one of my family or friends looking at it more than once. It’s a waste of time and effort.” – P15, Female, Age 42

Thus, we can see an important distinction between targeted sharing of media between two people and more ‘public’ sharing on sites such as Facebook. People were concerned because they did not know if the patients would be comfortable having others see them in their ill state.

Third, several participants talked about getting easy status updates on the health condition of the patient. They typically described it in a fashion similar to the way a person might post a status update to his/her Facebook wall. In this case, they wanted to know about health appointments, test results, and the patient’s well-being.
“The idea of a journal is interesting, more for other people in the family, not necessarily for the patient. A guestbook might be useful, where family and friends can write notes, kind of like wall posts on Facebook.” – P10, Male, Age 31

In Figure 20, we see the desire for P6, a caregiver, to design a tool with similar privacy settings as a Facebook page. In this drawing, three groups are noted, with the ‘admin’ group having the ability to decide on the health information to be shared with different social groups, such as family, close friends, and friends. There was a desire for an online space where individuals could view information, and ask questions or share comments with medical professionals.

Figure 20: P6’s drawing of desirable features within a health information sharing system

Again, we found that most participants were considerate of a patient’s privacy and wished for such messages to be shared only amongst a small close network of family or friends.
3.3. Results: Barriers to the Adoption of Existing Systems

The second part of the design study had participants evaluate six screenshots of four web-based tools, including two personal health record systems (PatientsLikeMe and Microsoft HealthVault) and two health information sharing systems (CaringBridge and LotsaHelpingHands). Participants stepped through each screen and annotated features they liked (using a green marker) and disliked (using a red marker). Once all six screens were annotated, participants were asked to rank their overall preferences for each screen, from Most Preferred (1) to Least Preferred (6). The results from these rankings are listed in Table 2.

<table>
<thead>
<tr>
<th>AGE</th>
<th>GENDER</th>
<th>RANKING</th>
<th>SCREEN OF SYSTEM AND KEY FUNCTIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>P01</td>
<td>28 M</td>
<td>[3, 4, 6, 1, 5, 2]</td>
<td>[A, B, C, D, E, F]</td>
</tr>
<tr>
<td>P02</td>
<td>39 F</td>
<td>[4, 3, 2, 1, 6, 5]</td>
<td></td>
</tr>
<tr>
<td>P03</td>
<td>31 M</td>
<td>[3, 2, 4, 1, 5, 6]</td>
<td>[A] CaringBridge: Photos</td>
</tr>
<tr>
<td>P04</td>
<td>54 F</td>
<td>[3, 6, 4, 2, 5, 1]</td>
<td>[B] CaringBridge: Story, Journal, Guestbook</td>
</tr>
<tr>
<td>P05</td>
<td>29 F</td>
<td>[4, 3, 2, 1, 6, 5]</td>
<td>[C] PatientsLikeMe: Home (Search)</td>
</tr>
<tr>
<td>P06</td>
<td>32 F</td>
<td>[3, 4, 2, 1, 5, 6]</td>
<td>[D] PatientsLikeMe: Charts, Symptoms</td>
</tr>
<tr>
<td>P07</td>
<td>61 F</td>
<td>[6, 2, 5, 1, 3, 4]</td>
<td>[E] Microsoft HealthVault: Home (Track, Share)</td>
</tr>
<tr>
<td>P08</td>
<td>21 F</td>
<td>[4, 2, 3, 1, 6, 5]</td>
<td>[F] LotsaHelpingHands: Home (Support)</td>
</tr>
<tr>
<td>P09</td>
<td>30 F</td>
<td>[6, 5, 2, 1, 3, 4]</td>
<td></td>
</tr>
<tr>
<td>P10</td>
<td>31 M</td>
<td>[5, 3, 4, 2, 1, 6]</td>
<td></td>
</tr>
<tr>
<td>P11</td>
<td>44 M</td>
<td>[5, 2, 3, 6, 1, 2]</td>
<td></td>
</tr>
<tr>
<td>P12</td>
<td>37 F</td>
<td>[5, 3, 4, 1, 2, 6]</td>
<td></td>
</tr>
<tr>
<td>P13</td>
<td>44 M</td>
<td>[3, 4, 2, 1, 5, 6]</td>
<td></td>
</tr>
<tr>
<td>P14</td>
<td>26 F</td>
<td>[3, 1, 4, 6, 2, 5]</td>
<td></td>
</tr>
<tr>
<td>P15</td>
<td>42 F</td>
<td>[4, 6, 3, 2, 5, 1]</td>
<td></td>
</tr>
<tr>
<td>P16</td>
<td>25 F</td>
<td>[4, 3, 2, 6, 5, 1]</td>
<td></td>
</tr>
<tr>
<td>P17</td>
<td>35 F</td>
<td>[3, 4, 5, 6, 2, 1]</td>
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</tr>
</tbody>
</table>

Table 2: Participants’ detailed rankings of systems

Figure 21 shows the median ranking of the sites from (1) Most Preferred to (6) Least Preferred. Thus, a low bar shows a stronger preference for the system. The error bar shows the range of responses from our participants. For example, for the CaringBridge Photos page [A], the median response by participants was 4, the lowest ranking was 3, and the highest ranking was 6. As seen in Figure 21, overall, participants had a strong preference for the PatientsLikeMe Chart page [D] because its bar is the shortest and the median centers around 1.
In contrast, the other sites revealed key concerns that people faced with the other commercial systems, such as Microsoft HealthVault [E] and LotsaHelpingHands [F], which both received median rankings of 5 from participants.

Figure 21: Median rankings of systems based on participant evaluations, from Most Preferred (1) to Least Preferred (6); error bars represent the range of rankings by participants

A more detailed view of the frequency of each system’s rankings is depicted in Figure 22. For example, for the CaringBridge Photos page [A], none of our participants ranked it as a 1 or 2; however, seven of our participants ranked it as a 3, five ranked it as a 4, three as a 5, and two as a 6. We can also see that the PatientsLikeMe Charts page [D] had the highest number of participants ranking it as most preferred (1). We now discuss findings for each system.
Figure 22: Frequency of participants' rankings of systems, from Most Preferred (1) to Least Preferred (6)
3.3.1. PatientsLikeMe

PatientsLikeMe received many positive reviews by our participants for its functionality and ease of use. Fourteen of our seventeen participants indicated either the PatientsLikeMe home page with search functionality or the PatientsLikeMe screen with charts and symptoms as their top two preferred (ranked as 1 or 2) screens. The site focuses on the idea of sharing experiences with illnesses with others globally. Users can search for information by disease and medication directly from the home screen. The site also provides functionality to have online discussions with others facing similar health situations, filtered by geographic location. Thus, in contrast to CaringBridge, LotsaHelpingHands, and Microsoft HealthVault, the focus is not on the patient per se. Participants described the large amount of information available with PatientsLikeMe as its best feature. This clearly shows that one of the major activities that people want to do when a family member has a chronic illness is to learn more about the illness.

“I like that it provides links where you can learn about your symptoms, explore different treatment options, find other people who have the same conditions and talk with them, share your experience. It kind of has an option for community on here and it encourages taking control of your conditions, being proactive.” – P1, Female, Age 28

“I love this one. It has all the information that I would personally go to the Internet for. You could actually plug in your information, figure out symptoms, prognosis; you’re not necessarily sharing things, doing all the bells and whistles, I just simply want information and there’s not a lot of clutter going on. You know exactly what you’re looking at.” – P2, Female, Age 39

In Figure 23, P2 notes her initial impressions of the PatientsLikeMe home page. We see that she liked the idea of secure login access, as circled in the top right of the screen. We also see that the simplicity of the search feature (located in the left side of the screen), including the two fields for users to enter their particular illness and medication, followed by two qualifying selectors (sex and age), is valued. The three-step description of the site in the middle of the screen is also circled as a desirable feature for its clarity and conciseness, along with the direct links to other patients, treatments, symptoms, research, and conditions listed on the right side of the screen.
Figure 23: P2’s evaluation of the PatientsLikeMe home screen

In Figure 24, P7 indicates that she liked the display of statistics using colour and bar graphs to denote the severity of the illness; however, she found the graphs depicting commonly prescribed medications and treatments to be confusing as the data was challenging to easily interpret. She also indicated that the list of age ranges was useful in seeing how she fit within the demographics of patients afflicted by the same illness.
Figure 24: P7's evaluation of the PatientsLikeMe statistics screen
3.3.2.  **CaringBridge**

Though CaringBridge received many criticisms for its design and purpose, participants ranked it within the middle of the systems. Fourteen of our seventeen participants indicated either the CaringBridge photos page or the CaringBridge story page with journal and guestbook features as their third or fourth preferred (ranked as 3 or 4) screens. The site focuses on the idea that users can create an online story about their loved one that is coping with a chronic illness. This would be similar to an online journal or blog. In CaringBridge, stories can include photos and textual descriptions. The intent is that stories can then be shared with family members so that they can stay aware of the condition of the patient. As can be seen in Figure 26, our participant liked the ability to share photos and suggested the ability to display even more photos than the one currently displayed. The participant also appreciated having the contact information about the patient’s medical facility readily available.

Others can even leave messages and comment on the postings. In Figure 25, our participant liked the narrative abilities and an area to share news and resources. However, she marked the social media icons as a feature she did not favour; this is a common theme we saw emerge when we discussed privacy concerns with our participants. While a few people liked the idea of an online journal, many participants described their hesitations with sharing personal health information in this way. Typical concerns focused on drawing unneeded attention to the patient and invoking additional worries.

“[My Story] I think is a great option, being able to journal and for people to leave messages. But I think for myself I wouldn’t use it that much. My mom’s really private about her condition and I think she would find it uncomfortable for me to be writing all about her, where friends and family can log in and see.” – P1, Female, Age 28

In Figure 25, P1 notes that the idea of the journal and guestbook can be useful by circling each in green. Yet as she is reviewing the screen and talking aloud, we learned that she would not likely use it for her mom’s condition due to concerns with privacy. We also see the desire for direct access to specific online resources about her mom’s condition, suggesting the value to include information about the illness.
“I think the centrality of the photos... in the context of my family, and my dad specifically; he would never ever want something like this. I think he’s just very personal and so making a page about him and what’s happening and having a community around him, he would, in some sense, feel like he’s putting more of a burden on people. And so to include photos and stuff would enhance that for him.” – P5, Female, Age 29

In Figure 26, P5 indicates that photos is not a necessary feature, though would consider the social aspects of the system, such as commenting, Facebook, Twitter, and YouTube if available with secure settings.
Figure 25: P1’s evaluation of CaringBridge’s MyStory screen
Figure 26: P5’s evaluation of CaringBridge’s Photos screen

These results build on the findings in our design activity where participants voiced their concern with sharing information about patients more broadly with other family and friends.
3.3.3. **Microsoft HealthVault**

Microsoft HealthVault received both positive and negative reviews from participants. Ten of our seventeen participants indicated Microsoft HealthVault’s home page as fifth or sixth preferred (ranked as 5 or 6) screens. On the one hand, people valued HealthVault’s focus on tracking and storing health information. Yet there were three primary issues that others had. First, some participants were concerned about the security of their data and associated the name, Microsoft, with a lack of trust, regardless of its actual trustworthiness.

“I don’t like this one very much at all. First of all it’s Microsoft. I would never use it; the second I found out it was Microsoft I wouldn’t want anything to do with it. I don’t trust that the information would stay private at all... that any of the information wouldn’t be sold to other healthcare organizations and all of a sudden I’d be getting emails for this, that, and the other. Zero trust. Zero interest in terms of the provenance of what this is.” – P2, Female, Age 39

“I think the layout is clean but I don’t like it that much because it looks like a product advertisement.” – P14, Female, Age 26

Second, some participants felt that the site had design issues in terms of organization, layout, and overall aesthetic appeal. This illustrates that participants thought about more than just functionality with the sites. The following quote also highlights a need to create a sense of ‘community’ within health recording and sharing sites.

“It’s not very well laid out. The feature I did like is that it tells you there’s privacy. For someone who’s looking at it for the first time, it wouldn’t be appealing. It’s not very well organized; the colors are very dull. It kind of has more of the hospital feel rather than the community-ish, welcoming, supportive thing.” – P8, Female, Age 21

"This one seems a lot less community-oriented. I know it says meet our friends and like us on Facebook, but a ‘Like’ on Facebook is not exactly like a community-thing.” – P10, Male, Age 31

Third, participants disliked the display of partner companies on the home page. This compounded concerns already voiced about the association with a large organization, Microsoft. In Figure 27, P13 circles his concerns in red, indicating his
disapproval of listing industry company logos, the dominance of Facebook and the repetitive login fields.

“I’m kind of lost. I’m not sure where I am here. I mean, it looks like they’re advertising for other things. It’s distracting. But if I want to be in here, I have to have an account or log in. I have no idea... I don’t like it. There’s more advertising here too. Why are there two of these (log in)? And Facebook? I don’t like that I come to this site, and I see people who clicked ‘Like’ show up here.” – P13, Male, Age 44

“I wasn’t a huge fan of the corporate sponsorship because I don’t think health and corporate goals should necessarily be connected. I don’t like to think about companies benefiting from the information. I just had a gut reaction; I didn’t like it.” – P5, Female, Age 29

These results demonstrate the importance of first impressions and functionality on the home page.
Figure 27: P13’s evaluation of the Microsoft HealthVault screen
3.3.4. **LotsaHelpingHands**

LotsaHelpingHands also received mixed reviews from participants. While six of our seventeen participants ranked the screen as their most preferred (ranked as 1 or 2) screens, nine of our participants also ranked it as their fifth or sixth choice (ranked as 5 or 6). First, participants found value in the core features of the site, which focuses on the social aspect of connecting people to provide or receive help from others. This could be in the form of information sharing or direct support through conversation. As can be seen, the focus here is similar to PatientsLikeMe.

However, the challenge that participants reported with LotsaHelpingHands was mostly related to usability and design. That is, most participants agreed that there were too many menu options, which made it challenging to decide where to navigate. Participants, such as P16’s evaluation in Figure 28, also noted that the colors and overall design of the site was weak.

“I don’t like the cursive text. I don’t like the colour either. It just doesn’t look very nice.” – P3, Male, Age 30

“The design looks a bit dated – the fonts, the style, the colors, the layout. The picture is not the greatest picture of mother and daughter. There’s a bit too much text, or it’s not presented in a way that sort of helps explain the purpose of the site.” – P10, Male, Age 31

“I don’t particularly like the colours on this. And I think there’s a lot of writing. I do like the box with the help section on the bottom.” – P14, Female, Age 25

This factored largely into their reactions to it and caused confusion over what the site was actually providing users.
Figure 28: P16’s evaluation of the LotsaHelpingHands home screen
3.4. Discussion

The findings from this study provided insight into barriers to the adoption of existing tools. First, because each of the sites focused on different types of functionality, we were able to identify what types of features were most liked by participants. In this case, we saw that participants, above all other features, valued being able to find out more information about the chronic illness and also to connect with other individuals who could provide further knowledge or contact. People appreciated quick, simple access to information within an online community. These features were found within PatientsLikeMe and LotsaHelpingHands. They also relate to participants’ drawings and discussions of desired features prior to seeing the sites.

Second, we see concerns with privacy and the degree of trust that people have with a particular company. Because we included systems from both well-known and lesser-known companies in our evaluation, we were able to draw understandings about each. Interestingly, a well-known company such as Microsoft had more issues with trust than lesser-known companies found with the other three sites.

Third, we also found that family members are careful about the way in which they project or display information about family members’ with chronic illness and recognize that creating personal online journals or posting photos may not be the most desired by the patients themselves. A similar finding was found in previous studies (Consolvo et al., 2004, Skeels, 2010, Skeels et al., 2010), yet now we see the issue still exists even when presented in a finished, polished product where corporate branding, marketing, and good design could sway views.

And, lastly, we learned that when comparing features, like other websites and software, people certainly consider the design of the site in terms of its likely usability (even before it is used!) and overall aesthetic design. In some cases, poor design can outweigh the inclusion of desired functionality.

Overall, these findings suggest value in the design of health information sharing systems that can connect people with more information about the health situation they are currently facing and building a sense of ‘community’ around the health problem.
3.5. Summary

In this chapter, I presented the findings from my design study that sought to investigate what features family members wanted in health information sharing systems to support the private sharing and management of personal health information in cases of chronic illness. We saw people valued being able to find information about the chronic illness and the status of the patient. Our summative evaluation also provided insight into barriers that inhibit the adoption of existing systems. Results showed that first impressions are important. People have a preference for sites that can provide them with access to information about the patient’s health condition. They also valued being able to share status information with a core group of people and getting additional information from a broader community of people online. Finally, we found that perceived trust with companies and good aesthetic design are important when it comes to the visual design of system features.

Prior work has sought to explore barriers to the adoption of systems such as Google Health and Microsoft HealthVault from a patient’s perspective (Tang et al., 2005, Liu et al., 2011). Findings revealed challenges in the usability of the evaluated systems and the need to design for a variety of users. My work extends these studies to more deeply understand desired tool and system features from a family member’s perspective.

The findings presented in this chapter provided a broad idea of family members’ desires for tools to help share health information, along with a detailed view of first impressions of existing tools. This is an important aspect to build on previous studies in order to better design technologies that will likely be used by both patients and family members. Specifically, we now have a clearer understanding of desirable features and concerns with the perceived usability of four existing systems. However, while this study provides a general view of features designers could integrate into systems, we do not have a solid understanding of the specific benefits of using various tools, or any costs that may be associated with such usage. This is the focus of the next chapter.
Next, I seek to understand which communication tools family members prefer to share such health information, and any associated costs that may result. In the next chapter, I describe the results of our second study focused on exploring the affective benefits and costs of synchronous and asynchronous communication tools for health information sharing.
4. Technology Preferences for Communication

In situations of a health crisis, family routines can become disrupted with the new requirement to focus on medical appointments and the ongoing treatment of the illness. Hindus et al. (2001) and Romero et al. (2007) have sought to design communication devices for the home. Past research has also shown that people often choose a combination of synchronous and asynchronous tools that are most familiar to them to communicate with each other (Grinter & Eldridge, 2001, Neustaedter et al., 2006). Families often use a combination of synchronous (telephone, video chat) and asynchronous (email, online forums) tools to communicate, resulting in varying degrees of closeness, awareness and social presence. The goal of this study was to investigate which types of technologies (synchronous and asynchronous) family members prefer to use for sharing health information (Research Goal 2). Despite prior work that completed varying comparative analyses of technologies, we do not yet know how they might translate to situations focused on sharing health information. Again, this is the focus of my research.

In this chapter, I present the results of the quantitative study that assesses the affective benefits and costs for two commonly used synchronous tools (telephone and video chat) and two commonly used asynchronous tools (email and Facebook). I begin with a description of the study’s methodology, followed by a statistical analysis of communication benefits and costs for each of the tools. I then present the measured ratings of benefits, including emotional expressiveness, engagement and playfulness, presence-in-absence, and opportunity for social support and measured ratings of costs, including feeling obligated, unmet expectations, and threats to privacy.
4.1. Methodology

In terms of technology evaluation, most studies of awareness systems and emotional connectedness utilize qualitative methods. For my research, the rigour of quantitative data supports the field of research where qualitative methods are most often used. There does exist a validated questionnaire called the Affective Benefits and Costs of Communication Questionnaire (ABC-Q) that allows researchers to compare communication technologies quantitatively (IJsselsteijn et al., 2009, Yarosh & Markopoulos, 2010). Using this questionnaire, I conducted a quantitative study to explore technology preferences for communication. I describe the ABC-Q in more detail in Section 4.1.2.

4.1.1. Participants

The same set of 17 participants completed the questionnaire; two participants’ responses to the questionnaire were incomplete and thus omitted during our analysis. This resulted in fifteen individuals between the ages of 21 and 61 (3 male, 12 female) participating in the study; the average age of participants in our sample was 37 years. These participants had experience with some form of basic technology, such as the use of telephone, computer, or online communication tools, such as email and Facebook. A more detailed breakdown of participant demographics is available in Section 3.1.1.

4.1.2. Affective Benefits and Costs (ABC) of Communication Questionnaire

Using the ABC-Q, we conducted a questionnaire-based study to compare the affective costs and benefits of synchronous and asynchronous communication technologies during situations of chronic health issues. To evaluate the most frequently used (and accessible) communication technologies, we selected two forms of synchronous technologies – telephone and video chat – and two forms of asynchronous technologies – email and Facebook messaging. These choices were also purposeful such that we could evaluate widely adopted tools, such as the telephone and email, while also considering technologies that have seen a recent uptake in usage by families, such as video chat (Judge & Neustaedter, 2010) and Facebook (Newman et al., 2011).
The questionnaire has excellent internal consistency (α = 0.96) and has been validated in previous studies of mediated awareness (IJsselsteijn et al., 2009). The original authors of the ABC-Q divided the questions into two dimensions: benefits and costs. Fourteen questions evaluated benefits of each communication tool based on levels of emotional expressiveness, engagement and playfulness, presence-in-absence, and opportunity for social support. Twelve questions evaluated costs of each communication tool based on levels of feeling obligations, unmet expectations, and threats to privacy.

Participants were asked to specifically focus on how they communicated health information about the chronic illness with a family or friend living in a different household. Here we asked participants to think of the family or friend with whom they most often shared the health information. Table 3 shows sample questions for ‘Benefits’ and ‘Costs’; a full list of questions is provided on the next page. For example, participants would be given the question in Row 1 and be asked to think about the person, [P], and the communication method, [M], that they were currently evaluating. Each question was measured on a 5-point Likert scale (1 = Never, 5 = Always).

<table>
<thead>
<tr>
<th>Benefits</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional expressiveness</td>
<td>Communicating with [P] using [M] helps me tell how [P] is feeling that day.</td>
</tr>
<tr>
<td>Engagement and playfulness</td>
<td>I have fun with [P] while using [M].</td>
</tr>
<tr>
<td>Presence-in-absence</td>
<td>Communicating with [P] using [M] helps me feel more connected to [P].</td>
</tr>
<tr>
<td>Opportunity for social support</td>
<td>Communicating with me using [M] helps [P] be there for me when I need them.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Costs</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling obligations</td>
<td>I worry that [P] feels obligated to contact me using [M].</td>
</tr>
<tr>
<td>Unmet expectations</td>
<td>I feel sad when [P] isn’t around when I try to contact [P] using [M].</td>
</tr>
<tr>
<td>Threat to privacy</td>
<td>I worry that others may overhear or see something that [P] and I share using [M].</td>
</tr>
</tbody>
</table>

*Table 3: Sample of questions where [P] = Person and [M] = Method of Communication*

Our reported mean values for costs and benefits represent the mean scored value by participants across all questions relating to costs and benefits. For example, for costs, we report the mean across all twelve questions asking about costs.
Affective Benefits and Costs (ABC) of Communication Questionnaire

**Directions:** Substitute the name of the communication medium for <M> and the name of the communication partner for <P> at the appropriate places in the survey. Participants should respond to each statement with: “Never,” “Rarely,” “Sometimes,” “Usually,” “Always,” or “Not Applicable.”

**Benefits (4 Scales – 14 items)**

*Emotional Expressiveness*
1. Communicating with <P> using <M> helps me tell how <P> is feeling that day.
2. Communicating with <P> using <M> helps me let <P> know how I am feeling.
3. Communicating with <P> using <M> helps me see how much <P> cares about me.

*Engagement & Playfulness*
4. I feel that contact with me using <M> is engaging for <P>.
5. I am excited about using <M> with <P>.
6. I have fun with <P> while using <M>.

*Presence-In-Absence*
7. Communicating with <P> using <M> helps me feel closer to <P>.
8. After we are done communicating, I still keep thinking back to something <P> shared using <M>.
9. Communicating with <P> using <M> helps me feel more connected to <P>.

*Opportunity for Social Support*
10. Communicating with <P> using <M> helps me provide <P> with social support.
11. <P> makes me feel special in our contact using <M>.
12. Communicating with me using <M> helps <P> be there for me when I need them.
13. Communicating with <P> using <M> when I am having a bad day helps me feel better.
14. Communicating with <P> using <M> helps me feel less worried about something.

**Costs (3 Scales – 12 items)**

*Feeling Obligated*
15. I worry that <P> feels obligated to contact me using <M>.
16. I have to talk to <P> using <M> even if I don’t want to.
17. I feel guilty if I don’t answer a contact <P> makes using <M>.
18. I have to answer when <P> tries to contact me using <M> even if I don’t want to.

*Unmet Expectations*
19. I feel sad when <P> isn’t around when I try to contact <P> using <M>.
20. I feel sad when <P> takes too long to respond when I try to contact <P> using <M>.
21. I worry that I am not meeting <P>’s expectations for our contact using <M>.
22. I feel sad when <P> doesn’t pay enough attention to me when we use <M>.

*Threat to Privacy*
23. I worry that <P> might learn something using <M> that I want to keep secret.
24. I worry about my privacy while <P> and I were using <M> together.
25. I worry that others may overhear or see something that <P> and I share using <M>.
  I worry that I am violating <P>’s privacy during our contact using <M>.
4.1.3. Procedure

For this quantitative study, participants were asked to complete an online questionnaire (Figure 29) consisting of 106 questions (2 demographic questions and 26 questions for each of the four communication tools). The first two questions helped us record the gender and frequency of use for each technology. It was important to record this information to assist in corroborating the data from this study with my qualitative study, where participants further explained why certain technologies were (and were not) used. A full overview of participant demographics and technology use for health information sharing is provided in Table 1. To ensure a consistent process, participants being interviewed via Skype were provided the URL link to the questionnaire immediately before the study was to commence.

Figure 29: Partial capture of online questionnaire (ABC-Q)
4.1.4. Hypotheses

Based on the previous literature, we see that people valued both synchronous and asynchronous communication technologies for different reasons and in varying situations (Grinter & Eldridge, 2001, Walther & Parks, 2002, Judge & Neustaedter, 2010). However, given that people are trying to achieve a high degree of emotional connection in situations of chronic health issues, and that they likely have limited amounts of time (e.g., trying to find out information about the illness and provide social support amidst an existing life routine), we hypothesized that:

**H1:** Synchronous methods of communication provide higher affective benefits to family members coping with a chronic illness than asynchronous methods of communication.

**H2:** Synchronous methods of communication incur higher affective costs to family members coping with a chronic illness than asynchronous methods of communication.

Thus, we predict higher ratings of affective benefits for health information sharing, including emotional expressiveness, engagement, presence-in-absence, and social support when using synchronous communication methods (telephone or video chat) as compared to asynchronous methods (email or Facebook) for health information sharing. We also predict higher affective costs of obligations, unmet expectations, and threats to privacy for the telephone or video chat when compared to email or Facebook for health information sharing.

4.1.5. Analysis Methods

Survey data was downloaded as a .txt file and imported into Excel for statistical analysis. Each answer was assigned a value on a 5-point Likert scale:

- 1 = Never
- 2 = Rarely
- 3 = Sometimes
- 4 = Usually
- 5 = Always
The four communication tools were independent variables: telephone and video chat were categorized as synchronous communication; email and Facebook were measured as asynchronous communication. A series of statistical tests were run as noted in each of the results sections.

The next section describes the results of this study, where I detail the affective benefits and affective costs of each of the four communication tools measured.

4.2. Results: Communication Benefits

The ABC-Q identifies emotional expressiveness, engagement and playfulness, presence-in-absence, and opportunity for social support as affective benefits of communication. Most participants reported high benefits of using the telephone to communicate health information (mean = 3.9, SD = 0.8, across all twelve cost questions). The second method of communication that yielded high benefits was email (mean = 2.9, SD = 0.9). Video chat (mean = 2.6, SD = 1.6) and Facebook (mean = 2.1, SD = 1.2) were ranked lowest of all technologies (see Figure 30).

![Figure 30: Ranked benefits and costs across technologies with error bars indicating standard error of the mean](image-url)
A one-way repeated-measure ANOVA showed that the effect of communication tool on benefits was significant, \( F(3,52) = 5.53, p = .002 \). Post-hoc analysis using a series of paired two-tailed t-tests (Table 4) across all possible communication medium pairs were performed to test hypothesis (H1) that the affective benefits for synchronous methods of communication would be higher than each asynchronous method.

### Table 4: Results of post-hoc two-tailed t-tests for affective benefits (blue indicates statistically significant results)

<table>
<thead>
<tr>
<th>Emotional Expressiveness (Affective Benefit)</th>
<th>T-Test</th>
</tr>
</thead>
<tbody>
<tr>
<td>Telephone vs. Email</td>
<td>( t(14) = 4.38, p = .0006 )</td>
</tr>
<tr>
<td>Telephone vs. Video Chat</td>
<td>( t(14) = 2.55, p = .023 )</td>
</tr>
<tr>
<td>Telephone vs. Facebook</td>
<td>( t(14) = 7.93, p = 0.000 )</td>
</tr>
<tr>
<td>Email vs. Video Chat</td>
<td>( t(14) = 0.246, p = .809 )</td>
</tr>
<tr>
<td>Email vs. Facebook</td>
<td>( t(14) = 3.97, p = .001 )</td>
</tr>
<tr>
<td>Video Chat vs. Facebook</td>
<td>( t(14) = 1.87, p = .083 )</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Engagement &amp; Playfulness (Affective Benefit)</th>
<th>T-Test</th>
</tr>
</thead>
<tbody>
<tr>
<td>Telephone vs. Email</td>
<td>( t(14) = 2.01, p = .064 )</td>
</tr>
<tr>
<td>Telephone vs. Video Chat</td>
<td>( t(14) = 2.25, p = .041 )</td>
</tr>
<tr>
<td>Telephone vs. Facebook</td>
<td>( t(14) = 3.56, p = .003 )</td>
</tr>
<tr>
<td>Email vs. Video Chat</td>
<td>( t(14) = 1.05, p = .310 )</td>
</tr>
<tr>
<td>Email vs. Facebook</td>
<td>( t(14) = 1.98, p = .068 )</td>
</tr>
<tr>
<td>Video Chat vs. Facebook</td>
<td>( t(14) = 0.604, p = .555 )</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Presence-in-Absence (Affective Benefit)</th>
<th>T-Test</th>
</tr>
</thead>
<tbody>
<tr>
<td>Telephone vs. Email</td>
<td>( t(14) = 4.32, p = .0007 )</td>
</tr>
<tr>
<td>Telephone vs. Video Chat</td>
<td>( t(14) = 3.08, p = .008 )</td>
</tr>
<tr>
<td>Telephone vs. Facebook</td>
<td>( t(14) = 7.02, p = .00001 )</td>
</tr>
<tr>
<td>Email vs. Video Chat</td>
<td>( t(14) = 0.26, p = .798 )</td>
</tr>
<tr>
<td>Email vs. Facebook</td>
<td>( t(14) = 1.69, p = .112 )</td>
</tr>
<tr>
<td>Video Chat vs. Facebook</td>
<td>( t(14) = 1.09, p = .292 )</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Opportunity for Social Support (Affective Benefit)</th>
<th>T-Test</th>
</tr>
</thead>
<tbody>
<tr>
<td>Telephone vs. Email</td>
<td>( t(14) = 2.73, p = .016 )</td>
</tr>
<tr>
<td>Telephone vs. Video Chat</td>
<td>( t(14) = 2.94, p = .010 )</td>
</tr>
<tr>
<td>Telephone vs. Facebook</td>
<td>( t(14) = 5.52, p = .00008 )</td>
</tr>
<tr>
<td>Email vs. Video Chat</td>
<td>( t(14) = 1.08, p = .297 )</td>
</tr>
<tr>
<td>Email vs. Facebook</td>
<td>( t(14) = 2.47, p = .027 )</td>
</tr>
<tr>
<td>Video Chat vs. Facebook</td>
<td>( t(14) = 1.09, p = .293 )</td>
</tr>
</tbody>
</table>
As predicted, using the telephone was rated to have significantly higher benefits than the asynchronous methods of both email (t(14) = 3.51, p = .003) and Facebook (t(14) = 6.16, p = .001). However, video chat did not show higher benefits than either of the asynchronous methods of email (t(14) = 0.80, p = .44) or Facebook (t(14) = 1.19, p = .25). That is, while the synchronous communication method telephone showed higher benefits than any of the asynchronous communication methods (email and Facebook), thus rejecting Hypothesis 1, the synchronous communication method video chat did not show any such benefit. Hence, Hypothesis 1 was rejected for video chat.

4.3. Results: Communication Costs

The ABC-Q identifies feeling obligated, unmet expectations, and threat to privacy as affective costs of communication. We also performed a one-way repeated-measures ANOVA to evaluate the effect of each communication tool on affective costs. This showed no significant difference, \(F(3,52) = 0.53, p = .66\). Given these results, we rejected our second hypothesis. This shows the tools do not have different affective costs associated with communication.

4.4. Results: Sub-Categories of ABC Questionnaire

Figure 31 shows a detailed breakdown of the values selected by participants for the groups of questions on the ABC-Q. Most prominently, the telephone was ranked highest in terms of all four types of benefits (emotional expressiveness, engagement & playfulness, presence-in-absence, and opportunity for social support). Rankings for email benefits were somewhat higher than the other technologies, though the differences were smaller. Video chat received similar benefits ratings as email in three of the four categories. Facebook scored lowest in all four aspects of communication benefits.
Figure 31: Analysis of mean benefits and costs across technologies with error bars indicating standard error of the mean
We conducted a one-way repeated-measure ANOVA on each grouping of benefits (Table 5). Each showed significant differences with p < .05. We conducted post-hoc analysis for each benefit category (using a paired two-tailed t-test) and found differences in all cases between the telephone and the other three mediums (p < .05). For emotional expressiveness and opportunity for social support, there were significant differences between email and Facebook (p < .05).

<table>
<thead>
<tr>
<th>Affective Benefits</th>
<th>ANOVA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional Expressiveness</td>
<td>F(3,56) = 7.60, p = .0002</td>
</tr>
<tr>
<td>Engagement &amp; Playfulness</td>
<td>F(3,56) = 3.09, p = .034</td>
</tr>
<tr>
<td>Presence-in-Absence</td>
<td>F(3,56) = 7.0, p = .0004</td>
</tr>
<tr>
<td>Opportunity for Social Support</td>
<td>F(3,56) = 5.58, p = .002</td>
</tr>
</tbody>
</table>

**Table 5: Results of ANOVA on affective benefits, (blue indicates statistically significant results)**

We also ran a one-way repeated-measure ANOVA on each grouping of costs and only noted a significant difference for ‘feeling obligations’ (Table 6). A post-hoc analysis on this affective cost grouping (using a paired two-tailed t-test) demonstrated differences in all cases between the telephone and the other three mediums (p < .05). Thus, people felt more obligated to communicate when using the telephone than the other technologies.

<table>
<thead>
<tr>
<th>Affective Costs</th>
<th>ANOVA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling Obligations</td>
<td>F(3,56) = 3.45, p = .022</td>
</tr>
<tr>
<td>Unmet Expectations</td>
<td>F(3,56) = 1.04, p = .382</td>
</tr>
<tr>
<td>Threat to Privacy</td>
<td>F(3,56) = 0.53, p = .666</td>
</tr>
</tbody>
</table>

**Table 6: Results of ANOVA on affective costs, (blue indicates statistically significant results)**
4.5. Discussion

While my findings suggest that a combination of existing technologies help individuals stay in touch with friends or family, most participants often used synchronous methods of communication to stay in touch. Overall, my quantitative study results show that for synchronous technologies, only the telephone provides more affective benefits than the asynchronous technologies of email and Facebook. What is interesting is the fact that the affective benefit rankings of video chat was not higher than the asynchronous technologies. This is despite previous studies showing people using video chat to provide emotional closeness over distance (Judge & Neustaedter, 2010). Subsequent chapters explore why this is the case through interviews with participants.

Real-time interactivity, whether in audio or video formats, provides a higher sense of emotional expressiveness, which is especially important when having conversations related to someone’s well-being. However, the telephone was also found to result in participants feeling obligated to connect with a family member. This might be attributed to the immediacy of synchronous communication. Interestingly, however, video chat was not rated to have similarly high levels of feeling obligated to connect, despite also being a synchronous communication method. This might be related to the finding that several participants used the phone to schedule a video chat meeting, in part due to the extra technological effort in setting up the video chat. As technological barriers of video chat decline, it will be interesting to see if the feeling of obligation will rise. The telephone also ranked highest in the affect of unmet expectations, where family members felt negatively about frequencies in contact or lack of attention.

The concern with asynchronous methods of communication is the lack of presence felt with delayed messages. This is also observed with participants who refrained from using the Facebook wall posting feature as a means to share health information, but opt to use the instant messaging feature built within.
4.6. Summary

In this quantitative study, we evaluated two synchronous and two asynchronous communication tools. Using an existing measurement tool, the Affective Benefits and Costs of Communication Questionnaire, we measured the affective benefits and costs of using the telephone, email, video chat, and Facebook for families sharing health information over distance. Our results demonstrated that the telephone and email, two widely adopted technologies, are most often used. The telephone was also confirmed to yield higher ratings of emotional expressiveness, engagement, presence-in-absence, and social support when compared to email and Facebook. It was also confirmed that the telephone incurred the highest costs of feeling obligated and unmet expectations, when compared to email and Facebook. When it comes to affective costs, people do not face any differences with the communication technologies. Yet at a more fine-grained level, we see that the telephone does produce more feelings of obligation for communication than the other mediums. We explore the reasons behind this more in the next study.

Much research has been conducted to understand preferred uses of synchronous and asynchronous technologies within normal, everyday family routines (Grinter & Eldridge, 2001, Hindus et al., 2001, Neustaedter et al., 2006, Romero et al., 2007). In family communication where health is not an issue, people prefer to use a combination of both types of technologies that are accessible, easy to use, and to coordinate video chat sessions that provide a greater sense of closeness. However, health situations change this because of the affective costs revealed in my study. While families coping with a chronic illness sought real-time conversations, synchronous technologies need to mediate the feelings of obligation (as seen with the telephone) and minimize threats to privacy (as seen with video chat).

In the next chapter, I describe the results of our third study focused on understanding the types of personal health information shared, how such information is managed, and the problems family members face when communicating within their family network.
5. Health Information Sharing and Routines

During the treatment of a chronic illness, family members often form a cohesive network of family and friends in which they share information about the health situation. In this chapter, I explore this information sharing and their relationships and report on the findings from the third study that had participants complete two activities: a paper-based task and a semi-structured interview. The goal of this study was to explore how and why people used each form of technology for sharing health information (Research Goal 3). More specifically, I sought to more deeply explore who health information was shared with, how and why the telephone and email were used by all participants to share information, and the reasons why video chat and Facebook were used less frequently. While prior research by Skeels (2010) describes the technologies most commonly used for health information sharing, it does not explore the rationale behind such usage or the ways in which the various technologies are used. Thus, we do not know where the tools might limit the activity of health information sharing. This is the focus of my study.

The results from this study are described as follows. First, I describe the methodology for the study. Then, I document the various roles that participants assumed as part of a health information sharing network. Third, I discuss how health information is managed and shared within a support network, including the ways health information is filtered to family members. Finally, I discuss the reliance on certain communication tools to disseminate health information across the support network.

5.1. Methodology

Creswell (2009) defines qualitative research as a “means for exploring and understanding the meaning individuals or groups ascribe to a social or human problem”. The current study had participants complete two activities: a paper-based task and an in-depth interview. Adopting a method used in prior studies to understand family
communication patterns (Farnham, 2005, Tee et al., 2009), we provided individual participants with a blank sheet of paper and asked them to draw an illustration that depicted their health information sharing network. The goal was to explore with whom family members shared information and how individuals were grouped in such a network. The purpose of semi-structured interviews was to then investigate how and why people used each form of technology for sharing health information within their networks (Research Goal 3). Again, triangulating findings from my two previous studies with this study will strengthen design directions and guidelines that result from this research.

5.1.1. Participants

The same sample as was used in the design study participated in this third study. A more detailed breakdown of participant demographics is available in Section 3.1.1.

5.1.2. Paper-Based Task

The first part of the study began with a paper-based task, which we used to visualize who family members included in their health sharing network while patients underwent treatment.

“Please draw a picture or map that shows how you are connected with all the people who you communicate with about <patient>‘s condition. Try starting by writing your name down and drawing a circle for you. Then draw some other people. You can draw them anywhere, but think about where you place them in relation to yourself.”

We intentionally provided a blank sheet to encourage participants to freely draw and organize their network as they wanted to represent. Participants were encouraged to include anyone with whom they shared or received information, as it related to the illness. Participants were also asked to consider the flow of communication and the tools used to communicate health information within their social network.

5.1.3. Semi-Structured Interviews

Following the paper-based task, we conducted semi-structured interviews, ranging from 90 to 120 minutes, in person with eleven participants and via Skype with six participants. Schensul et al. (1999) describe a semi-structured interview as one that uses
pre-formulated questions that solicit open-ended answers that can be further elaborated by either the interviewer or interviewee. We chose this method to produce data that could be further coded into domains, factors, and variables.

Participants described their (self-drawn) health information sharing networks, describing their motivations behind drawing their maps the way they did. We asked each participant to describe the topics outlined in Table 7. A full list of interview questions can be found in Appendix F.

<table>
<thead>
<tr>
<th>Topic</th>
<th>Sample Interview Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>Types of health information shared or received from certain individuals or groups and the methods in which they communicated</td>
<td>Looking at your family network, describe the types of health information you currently share/receive with certain individuals.</td>
</tr>
<tr>
<td>Role the participant had during the treatment of the chronic illness</td>
<td>What role do/did you have in this health crisis?</td>
</tr>
<tr>
<td>Relationships they had with individuals</td>
<td>Describe a particular moment in which you felt someone was especially helpful/considerate. Why?</td>
</tr>
<tr>
<td>Tools used to communicate within their health network</td>
<td>Of all the communication methods available to you, identify the tool you prefer to use in receiving/sharing health information. Why?</td>
</tr>
<tr>
<td>Impacts of the illness on their daily activities</td>
<td>Has the health condition impacted your schedule in any way?</td>
</tr>
<tr>
<td>Resources they found useful in coping with a chronic illness</td>
<td>Describe how you coordinate/manage household activities and tasks. Which tools do you use?</td>
</tr>
</tbody>
</table>

*Table 7: Topic and sample interview questions*
5.1.4. **Analysis Methods**

All interviews were audio-recorded and transcribed, resulting in 132 pages of typed, transcribed notes. A full list of interview questions can be found in Appendix F. Interview data was analyzed myself using open, axial, and selective coding (Strauss and Corbin, 1998). During the process of transcribing interviews, I assigned a code to any observation (e.g., [R] for role in health sharing network), and used that code to mark any recurrence of it. This process helped draw out similarities and differences across participants (e.g., [CFRD] for close friend); see Appendix H for a full list of codes. I then reviewed each observation to understand their context and causes of behaviours. An analysis of the coding led to the development of categories that was then further refined into core concepts.

As seen in Table 8, coding of participant drawings from the paper-based task demonstrated a variety of individuals within a health information sharing network. We often saw family [FAM], parents [PARNT], and close friends [CFRD] included, while others, such as church [CHUR] and strangers [STRAN] were noted in the drawings less frequently.

<table>
<thead>
<tr>
<th>Individuals in Health Sharing Network</th>
</tr>
</thead>
<tbody>
<tr>
<td>CFRD</td>
</tr>
<tr>
<td>CHUR</td>
</tr>
<tr>
<td>EXTFAM</td>
</tr>
<tr>
<td>FAM</td>
</tr>
<tr>
<td>FRD</td>
</tr>
<tr>
<td>MED</td>
</tr>
<tr>
<td>PARNT</td>
</tr>
<tr>
<td>PEER</td>
</tr>
<tr>
<td>SIBLING</td>
</tr>
<tr>
<td>SPVSR</td>
</tr>
<tr>
<td>STRAN</td>
</tr>
<tr>
<td>WORK</td>
</tr>
</tbody>
</table>

*Table 8: Analysis codes for individual roles in health sharing network*

Table 9 lists codes of health information participants shared within a network. During the interviews, participants often spoke about sharing appointment details [APPT], information about the illness [INFO], medications [MED], and treatment lifecycles [TRTMT]. Less commonly shared information included fundraiser details [FUND] and different moods [MOOD].
Next, I describe the results of this study, where I detail the various health sharing networks formed, the roles participants assumed within these networks, and the ways in which health information was shared amongst family members.

5.2. Results: Health Information Sharing Network

During the treatment of a chronic illness, we found that family members often formed a cohesive network of family and friends in which they shared information about the health situation. These networks were specific to the family member and their individual role in the situation. During the paper-based task, participants drew their health sharing networks in different ways; seven participants listed specific individuals while the remaining ten participants listed specific individuals and clusters of people (groups of contacts).

Participants’ drawings varied; I provide three sample drawings to depict some variations. To view all drawings, refer to Appendix H. A participant drew Figure 32 to identify individuals (wife, brothers, sister-in-law, parents, parents-in-law, aunt and uncle) and groups of people (cousins, friends, co-workers) with whom he shared information. The participant drew himself and his wife in the center, with connecting lines to specific people and groups. He also chose to include the technologies used to communicate with each person. We explore these preferences further in our semi-structured interviews.
The drawing in Figure 33 identifies individual members of a participant’s family (husband, sister, mother, dad, and extended family abroad), closest friends (names have been masked to preserve anonymity), other friends, and co-workers. When considering technology use, this participant chose to use an increasing number of lines to depict higher frequencies in communication.
Figure 33: P6’s drawing of her health information sharing network

Figure 34 illustrates a typical health information sharing network from our study where we see geographically-distributed family members living in India, France, Canada, and the United States. This participant included immediate family members, extended family members, close friends, and friends.

Figure 34: P15’s health information sharing network with communication tools
Our findings reveal that family members formed personal networks that were relatively close-knit, with an average of 10 people (median of 9.6, range of 3 to 29) or clusters of 3 groups of people (median of 2.7, range of 1 to 4). Table 10 outlines details of our analysis of the individuals and groups drawn by each participant.

As participants were provided a blank sheet of paper and asked to draw their networks as they deemed appropriate, some participants drew individuals, while others drew a combination of individuals and groups. For example, P10, our participant with the largest network, drew 29 individuals and 5 groups, comprised of extended family [EXTFAM], medical professionals [MED], peers [PEER], friends [FRN], and strangers [STRAN]. Refer to Table 8 for a full list of analysis codes for each grouping.

<table>
<thead>
<tr>
<th>Individuals and Groups in Health Sharing Network</th>
<th>Individuals</th>
<th>Groups</th>
<th>Groupings</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>P2</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>P3</td>
<td>9</td>
<td>4</td>
<td>[WORK], [FRD], [EXTFAM], [PARNT]</td>
</tr>
<tr>
<td>P4</td>
<td>4</td>
<td>3</td>
<td>[CHUR], [FRD], [MED]</td>
</tr>
<tr>
<td>P5</td>
<td>9</td>
<td>1</td>
<td>[PEER]</td>
</tr>
<tr>
<td>P6</td>
<td>8</td>
<td>3</td>
<td>[EXTFAM], [WORK], [FRD]</td>
</tr>
<tr>
<td>P7</td>
<td>7</td>
<td>3</td>
<td>[EXTFAM], [FRD], [CFRD]</td>
</tr>
<tr>
<td>P8</td>
<td>5</td>
<td>3</td>
<td>[EXTFAM], [MED]</td>
</tr>
<tr>
<td>P9</td>
<td>16</td>
<td>2</td>
<td>[EXTFAM], [FRD]</td>
</tr>
<tr>
<td>P10</td>
<td>29</td>
<td>5</td>
<td>[EXTFAM], [MED], [PEER], [FRD], [STRAN]</td>
</tr>
<tr>
<td>P11</td>
<td>10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>P12</td>
<td>12</td>
<td></td>
<td></td>
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<tr>
<td>P13</td>
<td>9</td>
<td></td>
<td></td>
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<tr>
<td>P14</td>
<td>14</td>
<td>4</td>
<td>[MED], [PEER], [WORK], [FRD]</td>
</tr>
<tr>
<td>P15</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>P16</td>
<td>7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>P17</td>
<td>11</td>
<td>5</td>
<td>[CFRD], [FRD], [WORK], [MED], [EXTFAM], [FAM]</td>
</tr>
</tbody>
</table>

Table 10: Analysis of health information sharing networks

5.2.1. Roles within Family Networks

Participants included groups of immediate family members, extended family, close friends, friends, and peers within their ‘sharing network’. These were the individuals with whom they would most regularly discuss the health condition, noting that work and/or school supervisors were informed on an ‘as-needed’ basis, such as when needing to reschedule shifts or extending deadlines.
“The people that I included on the map are the people I would, on a more regular basis, discuss her conditions with. The person I’m thinking of in this instance would be a co-worker, who I’m friendly with, but we don’t share a ton of personal information.” – P1, Female, Age 28

Some participants also included medical professionals in their network, depending on the frequency of communication. In our interviews, we asked participants to talk more deeply about the people with whom they shared health information. Our deeper analysis of individuals and groups in participants’ health information sharing networks revealed three communication roles, caregivers, local supporters, and remote supporters. These roles were often ‘softly’ established based on the geographic distance between family members and the patient. I describe these roles next.

5.2.1.1. Caregivers

Our data analysis revealed that there are individuals who live with a chronically ill patient and assist in the ongoing daily treatment of the illness. We call these individuals caregivers. Four of our participants were caregivers. Often, a parent of a young child or a spouse assumed this role.

“We have to balance a significant amount of things. Before, we’d just wake up, go to work, and do what we have to do. Now, we have to keep track of medication schedules, doctor’s appointments... figure out work schedules, taking leave or vacation so I can go to the hospital for any of the overnight or weekly stays.” – P3, Male, Age 32

Caregivers helped maintain patient health records that tracked symptoms, test results, medications and appointments. They were also familiar with domestic tasks and patient preferences for food and meals. We saw that caregivers had very detailed knowledge of the illness and treatment cycles and used a number of tools (e.g. calendars, to do lists, file folders) to manage the health information. We found that caregivers were privy to much more detailed information about a patient’s condition due to higher instances of in-person contact with the patient and medical professionals. With such daily interactions, there is little room to filter information.

Second to the patient, the caregiver often channelled details about appointments and health updates to other family members. Communication with the patient was mostly done in person because the caregiver was present with the patient so frequently.
Caregivers are similar to Skeels' (2010) proxy role, however, ours relates to health information sharing rather than providing social support. Skeels' (2010) proxy role is described as someone who interacts within a patient’s social network on their behalf.

5.2.1.2. Local Supporters

Our data analysis revealed that there are individuals who live in a different household but within the same city as the patient, making it possible for in-person communication. We call these individuals local supporters. Four of our participants were local supporters. Often, a child of an aging parent assumes this role and can provide regular physical support to the patient, including accompanying the patient to medical appointments or assisting with domestic activities such as shopping or cleaning.

“I took my mom to all the appointments. I translated all the documents that were given to us from the doctors. I feel that I was kind of a bridge between my mom and my sister. Gave a lot of information to my sister when she was away. I felt I had to keep everyone’s spirits up and take care of them.” – P6, Female, Age 32

“I’m the primary contact for helping my parents, for the care home and the contact for relaying information out to my siblings.” – P7, Female, Age 61

Local supporters focused more towards a patient’s medical appointments, often adjusting their own personal schedules to accompany patients to and from hospitals and clinics. This required methods to track healthcare facility locations and appointment times. Local supporters often expressed frustration with the lack of support from other family members and leaned to close friends for their own emotional support:

“My brother, I feel, is unsupportive in that he prioritizes work and other things over our father and his health.” – P5, Female, Age 29

“Because I was the one here dealing with it, even though I knew they wished they were here. I would just sometimes think, and still do, you should really come out more often and see how mom really is and how it affects dad. Sometimes I just feel like I’m the only one who has to deal with everything.” – P7, Female, Age 61

All four local supporters included a close friend on their health information-sharing network whom they relied on for emotional support. These close friends were often also
connected to the patient; however, with a more distanced relationship. We found that local supporters often adjusted their own personal schedules to accompany patients to and from hospitals and clinics. Information was shared with local supporters by the patient or caregiver, either in person or on the phone, given the geographic proximity. As such, it was rare to see technologies beyond the phone being used for this communication exchange. Local supporters differ from Skeels' (2010) coordinator role, often physically stepping in (rather than coordinating) to relieve caregivers of their role by accompanying patients to appointments. Skeels' (2010) coordinator role is described as someone who has limited access to information and only manages a specific scope of the support network.

5.2.1.3. Remote Supporters

Our data analysis revealed that there are individuals who live in a different city than the patient and rely on information from a caregiver or local supporter to maintain an awareness of changing health statuses. We call these individuals remote supporters. Nine of our participants were remote supporters. Often, remote supporters visit the patient soon after the diagnosis, but must return home after a short stay and rely on communication technologies to receive health information related to the patient and provide emotional support accordingly.

"It’s unfortunate I’m not there in person. I can’t do everything I wish I could do in person. Any information I find online, I email [to my sister]. Or I’ll call her and talk to her about it. I try to do whatever I can from a distance to make up for the fact that I’m not there to help." – P12, Female, Age 37

Remote supporters noted their struggle with filtered communication and the inability to have in-person conversations with patients and medical professionals. As a result, remote supporters typically resorted to using technologies most familiar to them to gain more information about the illness. Younger family members turned to online resources while older family members turned to medical professionals in their own location for expert advice. Eight of our nine remote supporters reported having made at least one visit to the patient’s city. The furthest participant away travelled from Canada to India to spend time supporting her father following heart bypass surgery, and her mother,
who required an equivalent amount of emotional support during the recovery period. We do not see a comparative role to a ‘remote supporter’ in any of Skeels’ work.

Overall, the three roles were often ‘softly’ established based on the geographic locations of family members relative to the patient. The following sections elaborate on the roles that each of these types of individuals took on, the ways in health information was acquired and shared within the support network, and the technologies used to share such information.

5.3. Results: Filtering Health Information

Patients often required help with everyday duties while managing the ongoing treatment of their illness and coping with the emotional impacts of the diagnosis. Yet, family members described instances when patients appeared to deliberately conceal their true health status. When people did share health information, people did find that such information shared amongst a family network existed at varying levels of granularity, and often was determined based on the roles (caregiver, local supporter, remote supporter).

Caregivers had access to the most knowledge related to the illness, including direct contact with medical professionals on behalf of the patient, and immediate awareness of changes in health states. Often, caregivers shared some of this health information with local supporters, including contact information of medical professionals and changes in patients’ health states. Remote supporters received the least amount of health information; it was seen that this group was aware of the illness and mostly was concerned with the changes in patients’ health states. Within these social groups, we also saw several interesting practices emerge around how information was shared or not with different generations. Impression management also factored into sharing health information. I discuss generational differences first, followed by impression management.

5.3.1. Generational Differences

In general, younger family members are comfortable with a range of communication technologies and their routines often include simultaneous use of multiple technologies to stay connected with each other (Grinter & Elridge, 2001, Grinter & Palen,
Yet, in our study, we often found that older family members made a conscious decision to limit, and sometimes exclude, their children (including adult children) from the granular details of a serious illness. This was despite the strong use of technology by younger family members and a constant ‘connectedness’ with others.

For example, P15 described how her children, aged 15 and 10, were aware of their grandfather’s (aged 72) hospitalization following a heart bypass surgery, but were shielded from the emotional impacts of the illness. Surprisingly, her children even helped install video chat software for her but were excluded from video chat session with the other family members about the surgery. Moreover, P15 also relied on her children to find and forward information online about symptoms following such a surgery.

“My children, they know what’s happening. During the operation, they knew what happened, but on a day-to-day basis we do not talk about it... it’s not a very pleasant subject.” – P15, Female, Age 42

P13 described how his children, aged 14 and 12, were excluded entirely from their grandmother’s (aged 67) diagnosis and treatment of breast cancer:

“It would be a discussion in house, between my wife and I. We left the kids completely out of it. Don’t tell them anything.” – P13, Male, Age 44

We even saw this pattern of filtering health information carried down from an even older generation to their adult children. For example, two participants (P15 and P13) expressed their frustrations with the limited amount of information they received from their aging parents, each coping with a form of cancer. Yet we saw P13, a remote supporter, behave similarly to his mom by excluding his own children from an awareness of the illness; his mother (aged 67) only informed him of her breast cancer diagnosis three months after the fact. He then relied on obtaining updates and information from his sister, the local supporter, who was in a better position to provide him with more detailed updates.

“They’re from a different generation... a generation that doesn’t tell you anything. They don’t tell you anything because they don’t want you to worry. They don’t want you to know that they didn’t ask the right questions... They just walk into it and just do whatever the doctors tell them.” – P13, Male, Age 44
P11, also a remote supporter, described his frustration with the trust his father (aged 72) placed on his family doctor, who misdiagnosed his terminal lung cancer, resulting in delayed treatment. Because P11 lived far away though, there was little he could do to help.

“There were a few months of progressively worsening symptoms and I was on the phone with them almost every day. But again, you’re dealing with the older generation and they have a different outlook on doctors and their role... I had gotten to the point where I threatened to physically manhandle him to go to a different doctor.” – P11, Male, Age 44

5.3.2. Impression Management

Family members described situations when patients were selective about what information was revealed about their condition in order to ‘preserve face’ and ‘maintain positive impressions’ (Khan & Markopoulos, 2009, Benjamin et al., 2012). P7, a local supporter, noticed the change in her mother’s behaviour as the symptoms of Alzheimer’s progressively worsened:

“A year ago she would talk a lot. Then it came to a point where she didn’t talk much at all because she knew she might say the wrong thing and not make sense. She was aware of it and she didn’t want people to know so she wouldn’t talk much. In general, she didn’t want people to know.” – P7, Female, Age 61

P2, a remote supporter, described how her mother (who suffered from multiple sclerosis) did not want to leave the house for fear of what others would think of her. She talked about communication with her mother’s caregiver, which was needed to shift her mother out of the denial stage of her diagnosis and encourage her to leave the house:

“She’s in denial to some degree. I know that she does know but she would rather wake up in the morning and pretend that things are the way they used to be. We’ve had to get her a wheelchair, which she really does not want to use. It’s getting really frustrating because she’d rather not leave the house then actually be seen in a wheelchair.” – P2, Female, Age 39

We observed another instance of impression management with P13, a remote supporter, who often communicated with his mom via Skype. However, once she started her chemotherapy treatments for breast cancer and began losing her hair, she would opt
for the telephone to connect, and ensured there were no pictures of her during the treatment stages:

“We did [Skype] quite a bit up to and before chemo but none in between. She lost all her hair. I was kind of selfish when I went to visit her before chemo – I wanted to see her as I knew her. And then the next time I saw her, her hair grew back. There are no pictures. And there are no pictures of her with the wig... she put herself in situations where there were no cameras. There were no pictures from that Christmas.” – P13, Male, Age 44

In general, family members were sensitive to patients’ insecurities about their chronic illnesses. We also found instances of impression management that related to the use of particular technologies. We discuss these in the next section that compares participants’ use and preferences for technologies.

5.4. Results: Communication Tool Usage

As also seen in our quantitative study described in Chapter 4, families often used a combination of synchronous (telephone, video chat) and asynchronous (email, Facebook) tools to communicate, resulting in varying degrees of closeness, awareness and social presence that result in their use. Across the various roles, we saw people had different technology preferences with varying reasons.

5.4.1. Preference for Synchronous Technologies

All participants used synchronous methods of communication, such as the telephone, to keep in touch with other family members. Table 1 outlines the technology uses for each of our participants revealed during the ABC Questionnaire conducted in our quantitative study. We uncovered that this communication mode was the most preferred because of the emotional nature of conversations. That is, people felt it was best to talk in real-time when discussing health information. The telephone, both landlines and cellular phones, were described as secondary in preference to in-person conversations due to convenience, mobility, and cost-effectiveness. Participants also emphasized the affordance of real-time conversations while having the option to use (asynchronous) text
messaging. In-person conversations were certainly easier for caregivers and local supporters than remote supporters, given their geographic proximity to the patient.

“If it can’t be in person, definitely over the phone. It’s real-time. So you’re actually getting people’s reactions, as opposed to just a sanitized version on the computer. You can hear inflection, voice tones, if someone’s crying. You wouldn’t know that on email.” – P2, Female, Age 39

“I prefer the phone because you get more information from what you’re not told than what you’re told. And you get more reaction the same way when you tell information because of tone of voice and pauses, and even breathing. A louder exhale of irritation versus one of relief...” – P13, Male, Age 44

Local supporters rarely used video chat because they would try to actually see the patient in person, rather than over a technology. There was a sense that, given the opportunity to see the patient in person, because they were in the same city, this should be done rather than trying to use video chat. Remote supporters, on the other hand, were more likely to adopt and use video chat because of the distance between them and the patient. Here video chat was used to enhance real-time conversations with a visual component: being able to see the person. Twelve of our participants reported using video chat capabilities of Skype to communicate in some form with members in their network. Most agreed on the benefits of simulating an in-person conversation with video chat:

“Skype is nice because you can see the person. It makes you feel a bit closer.” – P1, Female, Age 28

“It would be neat if we could have a web camera set up so that others can actually see her on a weekly basis. I’d like to be able to talk to them in person, to be able to see them, and they can see my reaction.” – P7, Female, Age 61

5.4.2. Video Chat Causes Commitment and Time Issues

Participants identified several downfalls of using video chat to share health information that did not come up in our quantitative portion of the study. These went beyond the ‘affective costs’ listed in the ABC Questionnaire (discussed in Chapter 4) and included the time commitment to: coordinate a time for a video call, set up the video connection, and then, subsequently, converse. Participants noted that video chat required
prearrangement and scheduling, including allocating a certain amount of time to the call and the obligation to be seated in front of the video window. This was seen to be a challenge for busy families, especially with children running around in the background, or adults needing to complete household chores during the call. These concerns made video chat secondary in preference behind the telephone.

“It’s better on the phone because you can multitask but with Skype you have to sit there continuously.” – P15, Female, Age 42

“For Skype it’s nice that we can see each other and that my aunt can see the girls, but sometimes it gets to be busy. With two small kids and all. They move around and so sometimes we’re off the screen and stuff.” – P3, Male, Age 32

“I don’t use Skype very often. I mostly use it at work for work-related purposes. I’m not using it very much for personal use. I’d rather talk on the phone. It’s just not my preferred method of communication with friends.” – P10, Male, 31

Thus, overall, even though family members wanted to feel close to the individual, which comes from seeing them (Judge et al., 2010), the social and time costs did not exceed the benefit. What was more beneficial than seeing the person, was the actual shared information about how the patient was doing. This is an important finding for future technologies to consider in balancing the affordances of video chat with the potential affective costs. This is discussed further in Chapter 6.

5.4.3. Moving Away from Talking and Face-to-Face

Family members described situations when patients were selective about what information was revealed about their condition in order to ‘preserve face’ and ‘maintain positive impressions’ (Benjamin et al., 2012, Khan & Markopoulos, 2009). First, we learned that video chat can be undesirable if the patient’s condition has deteriorated past a point in which she is comfortable having others see. Patients can use their technology choice as a way to engage in impression management and hide potentially sensitive views of them. For example, as seen when discussing instances of impression management, P13, a remote supporter, often communicated with his mom via Skype. However, once she started her chemotherapy treatments for breast cancer and began
losing her hair, she would opt for the telephone to connect. She also avoided having pictures taken of her during the treatment stages.

“We did [Skype] quite a bit up to and before chemo but none in between. She lost all her hair. I was kind of selfish when I went to visit her before chemo – I wanted to see her as I knew her. And then the next time I saw her, her hair grew back. There are no pictures. And there are no pictures of her with the wig... she put herself in situations where there were no cameras. There were no pictures from that Christmas.” – P13, Male, Age 44

In addition to this, people also spoke about limiting how much they talked with other people, either in person or on the phone. Again, there were issues of impression management where some patients did not want others to realize their condition was deteriorating. P7, a local supporter, noticed the change in her mother’s behaviour as the symptoms of Alzheimer’s progressively worsened:

“A year ago she would talk a lot. Then it came to a point where she didn’t talk much at all because she knew she might say the wrong thing and not make sense. She was aware of it and she didn’t want people to know so she wouldn’t talk much. In general, she didn’t want people to know.” – P7, Female, Age 61

Overall, we can see that people prefer face-to-face communication in person and on the phone because of the emotional nature of health information sharing. Yet there are times when it becomes too ‘costly’ to communicate these ways. That is, the privacy concerns of the patient supersede the need for others to know about the patient’s condition. A similar situation arises for video chat; however, video chat carries with it the additional issues of connection and timing. In cases where people opt to share less information in person or via synchronous technologies, it is not always the case that communication switches to asynchronous mediums.

5.4.4. **Email for Delayed Communication & Weak Ties**

All participants used email at some point to share health information; this depended on whom they were trying to contact within their network. Email was not seen as being able to provide as much emotional connection, but at times it was needed because of its asynchronous nature. Delayed communication was recognized to be more flexible as only one party needed to be available, thus opening up wider windows of
communication. Email also afforded the sender with the ability to prepare a message at any time of day. Thus, even though the information being shared is sensitive and emotional, the need for more asynchronous communication supersedes the sensitive nature of the information that suggests it should be communicated over the phone.

“Everyone has email. It’s pretty universal. And it’s easy; I can do it at any time of the day or night. At 2 AM, if I happen to be up, I can send them an email and don’t have to call them to wake them up.” – P12, Female, Age 37

Email was also used as a form of communication to connect with family members with weak ties. P5 described her choice to email her brother, who lived in the same city as her, to update him on their father’s health status:

“He can take a while to check his email so it can be slow for him to respond. Usually I just try to wait for a response, but if it’s something that needs to be dealt with immediately, I’ll follow up with a phone call. I would usually email him first and then use the phone. We don’t have a close relationship so it seems more of a buffer to use email.” – P5, Female, Age 29

P6 described her choice to email her extended family living overseas based on her weak relationship with them:

“It was just the easiest. Time difference. Comfort level. Yea, they are my family, but I don’t really know them that well.” – P6, Female, Age 32

People also described email as being good for sharing health information with a large number of weak ties in a single instance, despite the sensitive nature of the topic. That is, even in the case of discussing a patient’s passing, people would opt for email if they did not know the recipients well and there were a large number of people that needed to know the information. For example, P11 chose to use email to notify his father’s friends of his passing:

“I chose email because it was easiest to script – it was sort of a mail distribution, if you will. It was kind of a scripted letter.” – P11, Male, Age 44
5.4.5. **Online Social Media Sites**

When asked about the use of social media such as Facebook or other online forums as avenues for emotional support, we found that, regardless of age, people generally did not use them very often to share health information. Family members were sensitive to patients’ insecurities about their chronic illnesses and sites such as Facebook were seen as being too public, even for one-to-one messaging. There was a sense that even private messages within Facebook would be publicly visible. Some participants also did not know how to actually create private messages in Facebook.

“She knows that I also need to talk to people, but I have contained that to the smallest number of people while still getting what I need, because I could easily have shared stuff on Facebook. I know a lot of people do, but I think that’s an invasion of her privacy so if she wanted to, she could share it... on Facebook, that’s her decision, it’s not mine.” – P2, Female, Age 39

One participant expressed her preference of the physical presence and face-to-face interactions to discuss personal struggles rather than online postings.

“I don’t like sharing stuff on there, so I wouldn’t have said anything on Facebook. I don’t want it to be public. If anything, I might have used the instant messaging option on Facebook, maybe to talk to my sister about it.” – P6, Female, Age 32

As mentioned, participants were sensitive to patient privacy and often refrained from posting to social media sites like Facebook because of concerns with privacy. This further emphasizes that health information was shared amongst a small group of people as opposed to larger social networks that are found on sites such as Facebook. An overarching concern with asynchronous methods of communication was the lack of presence felt with delayed messages. Audio and video affords users with real-time interactivity, thus providing a higher sense of emotional connectedness; this is especially important when having conversations related to someone’s well-being.

5.5. **Summary**

In this chapter, I presented the findings from my qualitative study that sought to explore the health information shared and communication routines within a support
network. We saw that when families are faced with the challenges of sharing health information of a chronically ill patient, three roles are often established: caregiver, local supporter, and remote supporter. In these roles, family members also relied on certain communication tools to disseminate health information across a support network. Here we see that while distributed families communicate with both synchronous and asynchronous tools, there existed a reliance on synchronous methods as ways that yielded higher feelings of closeness. Yet, we also saw that asynchronous methods were valued for bridging weak ties and broadcasting messages. Finally, our results show that health information is shared within small social networks where information is filtered between generations and shared in specific ways that respect patient privacy.

Previous work by Civan et al. (2009) has provided an understanding of various roles family members and friends take on (conduit, contact broker, champion) to source expert resources about the illness on behalf of a patient. Skeels (2011) described commonly used technologies by patients to share health information and proposed administrator roles (proxy, coordinator) within a system designed to help share such information. My work extends these studies to understand these roles from a geographic sense and as defined by family members, in supporting a patient. We see that smaller social networks are maintained and that there are notable reservations with sharing private patient information with a broader group. As a result, to respect these concerns, family members avoid the use of certain technologies, such as video chat and Facebook.

In the next chapter, I summarize and discuss the design implications of the three studies completed as part of my research.
6. Design Implications

My overarching objective for this thesis was to provide an understanding of family members’ needs for sharing health information and a set of design guidelines that informs the design of technological systems to support awareness and communication between family members coping with a chronic illness. As evidenced in my previous chapters, my analysis of technology preferences and health information sharing routines stemming from my three studies extends prior research to present design opportunities for future systems.

This chapter outlines design implications derived from the findings of my three studies, beginning with understanding how to facilitate support from social networks. Next, I discuss design implications that consider providing family members with an awareness of a patient’s health status while respecting their presentation, privacy, and trust. Following that, I outline implications to address the communication needs and technologies for geographically-distributed family members. I then present design implications for designers to consider in the layout and usability of future commercial health information sharing systems.

6.1. Support from Small Social Networks

The three studies from this thesis show that people often want to connect and share information with small groups of individuals within their family and friends networks. In my design study, this was evident when participants analyzed the systems and were hesitant to use tools that promoted large scale sharing of information such as CaringBridge (Chapter 3, Research Goal 1). In my quantitative study, this reoccurred when people were concerned about using systems like Facebook where content might be visible by large groups (Chapter 4, Research Goal 2). In my qualitative study, this
specifically came to focus when people drew their sharing networks and nearly everyone's contained less than 10 people in it (Chapter 5, \textit{Research Goal 3}).

Hartzler et al. (2011) found that cancer patients reported sharing diagnosis and treatment information with an average of 75-97 people from their social networks. My findings contrast this finding (quite drastically), with our participants only identifying regular and trusted contacts with whom they would most often connect with for social support (median of 9.6 individuals, range of 3 to 29). We see a similar finding in Neustaedter et al. (2006), whose study identified a median number of 13 individuals within an extended social circle (casual relationship). Hartzler et al. likely had different results because their work involved patients’ perspectives. My research extends this prior work by studying sharing networks from a family member’s perspective (rather than from a cancer patient’s perspective). The variation in network size suggests that family members are more conscious about sharing patient’s personal health information.

Thus, across all three of my studies, we see the same general result. This suggests that designs for supporting the sharing of health information amongst family members should really be focused on sharing information between a small number of people, likely less than 10 given the findings in my qualitative study.

\section*{6.2. Self-Presentation, Privacy, and Trust}

My findings also revealed that patients were self-conscious of their conditions, often going to great lengths to maintain a certain level of privacy and self-presentation (Chapter 5, \textit{Research Goal 3}). Benjamin et al. (2012) also reported that older adults were selective with the information they shared about their chronic pain, often refraining from revealing pain to reflect themselves positively (impression management) (Goffman, 1959). Skeels (2010) echoes these findings with patients revealing far less health information with their immediate families so as to not have them worry. My work extends prior studies by providing family members’ perspectives on sharing patient information. Our participants speculated that patients did not want to burden their loved ones with their illness and often only shared detailed health information with their caregivers (Chapter 5, \textit{Research Goal 3}). Maintaining a small network helps to mitigate concerns
that patients have with privacy and impression management where family members must be sensitive to the private nature of illnesses. This suggests the need to design systems that allow for sharing health information with varying degrees of privacy settings.

In my design study, we saw that people were concerned about whether patients would be comfortable with having others maintain online journals, post photos, and share updates on ‘public’ sites such as Facebook on their behalf (Chapter 3, Research Goal 1). Additionally, my quantitative study revealed that Facebook was rated as having the highest affective cost of feeling threats to privacy across the four technologies evaluated (Chapter 4, Research Goal 2). This finding was echoed in my qualitative study when participants perceived that sharing health information on Facebook was risky and would only use the built-in private message or instant messaging features (Chapter 5, Research Goal 3).

My studies also revealed concerns with privacy and the degree of trust that people have with a particular company. This is similar to a finding by Liu et al. (2011) whose study revealed patients’ sentiments of distrust with Google Health’s affiliation with the large Google search engine. Interestingly, a well-known company such as Microsoft had more issues with trust than lesser-known companies found with the other three sites. The results of my design study noted that several participants had an instinctive reaction against trusting Microsoft HealthVault due to its association with the corporation, Microsoft, and the listing of multiple industry companies on the home page (Chapter 3, Research Goal 1). My work extends this past research by further exploring family members’ concerns with trusting the true motives of a large corporation’s interest in securing confidential patient data (Chapter 5, Research Goal 3). This suggests that large corporations designing systems should consider the prevalence of their brand and logo in order to overcome issues with trust that users may have.

The triangulation of findings from these three studies suggests the need for system designers to consider ways to share personal health information with select social groupings to ensure self-presentation and patient privacy. The idea of organizing network groupings is not a new idea, as evidenced in popular social network grouping capabilities (Facebook ‘lists’ and Google+ ‘circles’). However, in situations of a chronic illness, it is especially important to streamline the process of creating such groups to suit the roles
within a close-knit health information sharing network. My research more clearly identifies such roles (caregivers, local supporters, remote supporters) that system designers can refer to design appropriate security and privacy settings.

6.3. Communication Needs and Technologies

Communication needs for families coping with a chronic illness differed from routine family communication practices in their consideration for the sensitive nature of the conversation. That is, because people were often discussing emotional topics, they needed to keep this in mind when choosing how they communicated with others. The most valued communications involved a clear, meaningful personal effort on behalf of the sender, which could come in the form of real-time conversations or thoughtful messages. This is similar to findings by Romero et al. (2007) for family communication in general. Skeels (2010) found that the most preferred method of communication for patients was to talk in person when it comes to sharing health information; however, this is not always possible in cases of distributed family members. My work extends this prior work by more deeply exploring the rationale behind communication routines and preferences for certain technologies to mediate geographic distance.

Participants also described that the timing of information exchange was highly valued. My studies revealed that both synchronous and asynchronous technologies were important for family members, depending on the situation (Chapter 4 and 5, Research Goal 2 and 3). I discuss each of these tools in the following sections.

6.3.1. Synchronous Communication Tools

In some instances, real-time conversations or support are critical. For example, in a situation where a close relative needs to help make a major decision, synchronous communication would be important. My studies demonstrated that synchronous methods of communication yielded the most benefits due to its real-time nature, portability, and ease-of-use. Specifically, in both my quantitative study and my qualitative study, participants expressed that the telephone provided the highest affective benefits for communication over distance (Chapter 4 and 5, Research Goal 2 and 3). Real-time interaction, whether with voice or video, provides a higher sense of emotional
expressiveness, which is especially important when having conversations related to someone’s well-being. However, the telephone was also found to result in participants feeling obligated to connect with a family member. This is attributed to the immediacy of synchronous communication. One design implication would be the inclusion of a system feature that would connect family members with patients that affords the convenience of a mobile phone while lowering feelings of obligation.

Interestingly, in my quantitative study, video chat was not rated to have similarly high levels of feeling obligated to connect, despite also being a synchronous communication method and being obligated to stay in front of the camera during the conversation (Chapter 4, Research Goal 2). In my qualitative study, it was evident that seeing patients, either through photos or a video chat system, was desired, as participants felt closer, despite any physical distance that separated them (Chapter 5, Research Goal 3). However, as several participants described, coordinating a video chat session was cumbersome and there was extra technological effort to set up the video chat software.

Also in the interest of patient privacy seen in the previous section, family members did not want to place too much attention on the patient using video chat. We saw that video chat was sometimes seen as being problematic because of patients’ concerns over their appearance (Chapter 5, Research Goal 3). Together, this suggests that technologies such as video chat — where feelings of closeness come from seeing another person (IJsselsteijn et al., 2009, Judge & Neustaedter, 2010, and also shown in Chapter 5) — may not always be an appropriate medium for sharing health information. Instead, systems focused on audio or textual exchanges may be most comfortable amongst family members and patients. If patients or family members do want to use video chat tools such as Skype, designers should aim to develop these systems in a way that allow patients to control confidentiality and only show themselves, or their surrounding environments when they are comfortable revealing it.

Thus, overall, we see that though synchronous methods of communication enable family members to feel close to the individual, which comes from seeing them (Judge et al., 2010), there were barriers to the adoption of such tools. As the technological barriers of video chat decline, it will be interesting to see if the use of video chat increases or if the
feelings of communication obligation will rise. This suggests that designs for communicating health information synchronously should be integrated into systems in such a way that minimizes technical complications and displays a family member’s availability for communication.

To address concerns users have with the technical set up of video chat, systems must be designed with simple guided procedures to activate a video connection. For example, an integrated system would enable a user to simply sign in to a system and select whether they wish to be available for a video call, and to accept or initiate a video chat session without requiring any additional log in or hardware set up.

Systems will also need to allow users to select and share availability states with other members of their sharing network. Nardi et al. (2000) studied availability indicators for instant messaging tools and suggest that such indicators do not always accurately reflect users’ actual states as users typically resort to the default setting. As a result, such indicators do not effectively negotiate a user’s availability for communication. Existing tools, such as Skype, GTalk, and other instant messaging tools provide similar availability states (e.g., ‘Online’, ‘Available’, ‘Busy’, ‘Away’, ‘Offline’, etc.), however all of these tools were individually designed. Consequently, none of these tools display availability states across all possible communication tools. A design opportunity would be for systems to provide a consolidated view and opportunity for a family member to choose their state per communication tool (video chat, telephone, email, instant messaging, text messaging, in person, etc.). For example, such a view could display that a caregiver could note that he was available for email and text messages, but unavailable for telephone calls and video chat sessions. As seen in Nardi et al.’s (2000) work, the challenge with such indicators is the unreliability with systems changing states. Future research will need to figure out a way for people to actually change their state and for systems to reliably predict when to automatically change a user’s availability state.

6.3.2. Asynchronous Communication Tools

In other instances, such as when a friend wants to provide encouraging messages to the patient, or where family members would like to avoid direct communication with each other for various reasons, asynchronous communication tools are valuable. In
situations where there is need for solitude, asynchronous tools may be most appropriate so that family members can regulate their autonomy and choose when and how they communicate with others (Chapter 4, *Research Goal 2*). This could be especially important when a patient is critically ill. During my qualitative study, people also described email as being ideal for sharing health information with a large number of weak ties in a single instance, despite the sensitive nature of the topic (Chapter 5, *Research Goal 3*). Overall, my studies suggest that even though the information being shared is sensitive and emotional, systems should include asynchronous communication tools to enable sharing health information across geographic distances and to mitigate concerns with feeling obligated to connect (which is apparent with synchronous communication tools).

Overall, my studies in this thesis suggest that when designing communication technologies for health information sharing there is no ‘one size fits all’ solution. Future system designs will need to include features typically found in synchronous and asynchronous communication technologies. For example, referring back to the design implication for a consolidated view of availability states across all possible communication technologies, users should be able to select to be available via video chat (synchronous) and email (asynchronous) and be able to easily migrate between the two accordingly.

Another possible technical innovation would be the automatic parsing of calendar events and chronic illness medication and treatment information to represent this data in a way that is easily comprehensible. For example, a health information management system that includes communication tools could be designed to store medical appointments in a calendar and display a family member’s availability for communication based on this information. A member of the sharing network could then see that someone may have just returned from a chemotherapy appointment and determine that the timing of a video chat session may not be appropriate. Additionally, subsequent conversations could then be more targeted as a result.

### 6.4. The Design of Commercial Systems

Given the implications I have discussed in this chapter, we can see that retrospectively, the four systems that I evaluated in my design study only partially meet
the design suggestions. For example, CaringBridge provides some of the narrative journaling abilities that several participants desired, but did not have the privacy controls participants sought to respect patient privacy. We also see that while PatientsLikeMe was highly ranked for the online community support and wealth of information, it did not provide the more granular options to share health information with a smaller network. While Microsoft HealthVault is a well-known technology corporation, its affiliation with Microsoft had negative impacts on the adoption of its system. Finally, LotsaHelpingHands focuses on the social support aspects desirable to feel connected to patients, yet the system remains limited in its design and usability.

The results of my design study point to several key themes. First, because each of the sites focused on different types of functionality, we can see what types of features were most liked by participants. In this case, we saw that participants, above all other features, valued being able to find out more information about the chronic illness. (Chapter 3, Research Goal 1). During my qualitative study, several participants further explained that they often first turned to online resources to learn more about the illness or to connect with strangers who were more familiar with symptoms and treatments (Chapter 5, Research Goal 3). This suggests the need to provide search functionality to parse a large amount of information related to the illness, symptoms, medication, and treatment.

Second, we see that participants want to connect with other individuals who could provide further knowledge or contact. People appreciated quick, simple access to information within an online community. These features were found within PatientsLikeMe and LotsaHelpingHands, where participants described the large amount of information available with PatientsLikeMe as its best feature (Chapter 3, Research Goal 1). However, there was a clear distinction between connecting with a broader community to share general information about the chronic illness and connecting with a smaller, close-knit network to share personal information about the patient (Chapter 5, Research Goal 3). Again, this reinforces the need for systems to incorporate less complex privacy controls to enable the sharing and filtering of health information according to various social groups.
Third, several participants, regardless of their role of caregiver, local supporter, or remote supporter, sought access to a comprehensive, centralized list of contact information, such as key family members and medical facilities (Chapter 3 and 5, Research Goal 1 and 3). Participants also appreciated simple status updates on the health condition of the patient, similar to the way a person might post a status on his/her Facebook wall (Chapter 3, Research Goal 1). However, system designers should be well aware that family members are careful about the way in which they project or display information about family members’ with chronic illness. A similar finding was found in previous studies (Consolvo et al., 2004, Skeels, 2010, Skeels et al., 2010), yet now we see the issue still exists even when presented in a finished, polished product where corporate branding, marketing, and good design could sway views. Securely sharing health information amongst various social groups is a reoccurring implication that system designers should address.

Lastly, in my design study, we learned that when comparing features, like other websites and software, people certainly consider the design of the site in terms of its likely usability (even before it is used!) and overall aesthetic design (Chapter 3, Research Goal 1). Participants further described their concerns with existing commercial systems during the qualitative study (Chapter 5, Research Goal 3). In some cases, poor design, including colour and photo choices, overall layout, and information structure can outweigh the inclusion of desired functionality.

Overall, these findings suggest value in the design of health information sharing systems that can connect people with more information about the health situation they are currently facing and building a sense of ‘community’ around the health problem.

6.5. Summary

In this chapter, I provided an understanding of family members’ needs for sharing health information and a set of design guidelines that informs the design of technological systems to support awareness and communication between family members coping with a chronic illness. Based on findings from all three studies that form this thesis, this
understanding and set of guidelines is comprised of four main design implications to assist in the design of future commercial health information sharing systems.

My first design implication suggested that systems should be designed in such a way to enable sharing private health information amongst a small social network. On this same note, less personal health information should be shareable with a larger group, suggesting the need for granular privacy controls. My second design implication suggested that systems should provide functionality that would respect patients’ concerns with how they are presented to a particular network. This included privacy controls for online journals, photos, status updates, and contact information. My third design implication suggested that systems should integrate a combination of synchronous and asynchronous communication tools to help connect patients, caregivers, local supporters, and remote supporters. We saw that there is evidence of benefits of both types of tools, including real-time (synchronous) interactivity, and flexibly timed (asynchronous) communication. My final design implication suggested that systems should consider the design and usability of their interfaces. First impressions were important; users notice colour and photo choices, and sought concise, clear, accessible information.

In the next chapter, I conclude this thesis by placing the findings from my three studies and design implications outlined in this chapter in the context of my original research goals. I also reflect on the research contributions I have made to the areas of health information sharing and domestic computing.
7. Conclusion

This thesis has explored the technology preferences and routines of geographically-distributed family members coping with a chronic illness. The goal of this final chapter is to conclude my thesis by summarizing the research problems and describing the completed objectives that form my research contributions. I then discuss next steps of designing technologies to support health information sharing and domestic computing research that can build on this thesis’ work.

7.1. Research Objective

This thesis focuses on addressing the overarching research question: *how can we best design health information sharing systems to support the communication routines of family members coping with a chronic illness?* This question was divided into three sub-problems in Chapter 1 that looked at the design of health information sharing technologies from a broad to narrow perspective:

**Research Problem 1:** We do not have a detailed understanding of what features people desire in commercial systems to help manage and share personal health information within a family network.

**Research Problem 2:** We do not have a detailed understanding of what preferences people have for technology within the context of sharing health information.

**Research Problem 3:** We do not have a detailed understanding of what types of personal health information is shared, how the information is managed, and the problems family members face when communicating about such information.
7.2. Research Contributions

The main objective of this thesis was to provide an understanding of family members’ needs for sharing health information and a set of design guidelines that informs the design of technological systems to support awareness and communication between family members coping with a chronic illness. I completed this objective by addressing each of the previously mentioned research problems with three research goals. These present a number of significant research contributions to the fields of HCI, domestic computing, family communication, and, more specifically, health information management. I outline the three goals, the steps I took to complete them, and the research contributions they present.

7.2.1. Commercial Health Information Systems

Research Goal 1: Investigate what features family members want in commercial health information sharing systems to support the sharing and management of personal health information in cases of chronic illness.

I have completed this goal by conducting design studies and summative evaluations of existing commercial systems with 17 participants, analyzing the findings using open, axial, and selective coding, and synthesizing the findings to inform the design of future systems. The completion of Research Goal 1 presents several major research contributions, including the understanding of tools to support sharing of health information, identifying the barriers to the adoption of existing systems, and informing the design of future systems.

In Chapter 3, we see that participants appreciated the ability to search for additional information and support resources online within a health information sharing system. We also uncover that there is a desire to visually see a patient, either through photos or video chat tools, but system designers would have to be cognisant that such functionality would need to be equipped with secure controls to address concerns with patient privacy. Additionally, participants expressed their interest in maintaining an awareness of a patient’s health status, including having knowledge of a patient’s appointments, test results, and their overall well-being.
In order to best design systems that will be adopted by families coping with a chronic illness, we now have a clearer understanding of barriers to the adoption of four existing commercial systems, PatientsLikeMe, CaringBridge, Microsoft HealthVault, and LotsaHelpingHands. Chapter 3 outlines concerns with the sharing of too much patient information, including photos and journals, both within the system, and via social media links, such as Facebook, YouTube, and Twitter. We also see that corporate sponsorship, either with large technology firms such as Google and Microsoft, or industry partners, impacts the trust in maintaining confidential patient data in such systems. Finally, we see that overall aesthetic design impacts the adoption of systems, where poorly chosen colours, images, and layout would inhibit the use of such tools.

Past research has only shown the barriers to the adoption of existing systems (Tang et al., 2005, Liu et al., 2011), thus my work extends such studies to more deeply understand desired tool and system features from a family member’s perspective. With a deeper understanding of the requirements for sharing health information and barriers to the adoption of existing systems, designers can now consider such implications in the design of future systems to address such requirements.

7.2.2. Technology Preferences for Communication

Research Goal 2: Investigate which types of technologies (synchronous vs. asynchronous) family members prefer to use for sharing health information in cases of chronic illness.

I have completed this goal by conducting online surveys with the same set of 17 participants using a validated Affective Benefits and Costs of Communication Questionnaire (ABC-Q), analyzing the findings using statistical tests, and synthesizing the findings to understand the preferred synchronous and asynchronous communication tools for sharing health information. The completion of Research Goal 2 presents several major research contributions, including an understanding of communication benefits and communication costs.

In Chapter 4, participants revealed the desire to use synchronous and asynchronous communication tools interchangeably. Understanding which tools incur affective communication costs will assist system designers in integrating appropriate
technologies within a health information sharing system. Despite providing high affective communication benefits, Chapter 4 also revealed that the telephone incurred the highest costs of feeling obligated to connect with another family member and unmet expectations. Facebook was found to have the highest concern with threats to privacy.

Past research has shown comparative analyses of synchronous and asynchronous technologies (Grinter & Eldridge, 2001, Hindus et al., 2001, Neustaedter et al., 2006, Romero et al., 2007), thus my work extends these studies to more deeply understand these preferences within the context of sharing health information when coping with a chronic illness. A clearer understanding of specific synchronous and asynchronous communication tools when sharing health information within a domestic network helps inform the design of technologies that consider the benefits while mitigating the costs of such tools.

7.2.3. Health Information Sharing Routines

Research Goal 3: Describe the communication routines of family members when sharing a patient’s personal health information in cases of chronic illness.

I have completed this goal by conducting paper-based tasks and semi-structured interviews with the same set of 17 participants, analyzing the findings using open, axial, and selective coding, and triangulating the findings with data from my design study (Chapter 3) and my quantitative study (Chapter 4). The completion of Research Goal 3 presents several research contributions, including an understanding of health information sharing networks, roles within family networks, how family members filter health information, and communication tools used to share health information.

In Chapter 5, we see that participants formed small, close-knit networks that included individuals ranging from co-workers, extended family members, friends, and medical professionals. The composition of these networks varied, depending on the participant’s role (e.g. caregiver, local supporter, or remote supporter). Such a finding enables system designers to consider the structure of health information and its relationship with system roles and administration. We also see the importance of establishing granular permissions to ensure secure filtering of health information amongst a network.
Notable work by Skeels (2006) describes commonly used technologies for sharing health information; however my work extends these studies to understand the rationale for using a variety of technologies and to identify where such technologies may limit the activity of sharing health information. While the ABC-Q provided quantitative insight into preferred tools, we further explored preferences for certain communication tools. Specifically, we obtained more detailed reasons as to why video chat was not often used in the context of sharing health information. Despite its ability to provide a greater sense of closeness (IJsselsteijn et al., 2009, Judge & Neustaedter, 2010), setting up the technical software and hardware and coordinating a video call posed challenges to some participants. System designers can now consider ways to integrate the benefits of video chat while mediating set-up and scheduling.

7.3. Limitations and Future Work

This thesis offers important contributions to other researchers and designers exploring the space of personal health information management and sharing; however, I acknowledge the limitations of the work. The largest of these is the fact that we did not have any patients in our sample. Because of this, our results do not describe patients’ preferences for personal health information sharing with family members and friends. This is especially critical in considering impression management and delegation of roles within a system. Future work should triangulate our findings of caregiver and supporter roles with patient roles.

Second, I acknowledge that people may be more comfortable using certain technologies and this may affect their perceived level of affective benefits and costs in their ratings. For example, video chat may not be ranked positively as it requires a certain level of technical knowledge to install required hardware and software. Future work should consider assessments of participants’ familiarity with certain tools.

Third, I realize that our sample pool included individuals whose health situations occurred within the past five years. During this time, technologies have evolved dramatically and user adoption and novelty of tools should be accounted for. Future
studies should consider the evaluation of current tools involving families whose health situations are also current.

Finally, while we believe our results will generalize across all relationships, we acknowledge that our sample size was limited and we only had participants consider their interactions with one remote family member or friend. Given this, participants may be closer in distance to certain individuals, which may influence the technologies used. For example, video chat may often be used to connect with individuals who live in different cities (but similar time zones), as they often do not have the flexibility of physically seeing each other as individuals who live in the same city. Thus, the distance between people could present one potential confound. Conversely, living in different time zones might result in higher usage of asynchronous communication methods. Future work should more deeply explore geographic distances that separate family members to understand the impacts on maintaining such relationships.

This research may be extended with further studies evaluating patient preferences for health information sharing. Understanding these perspectives will assist in ensuring security controls that would address privacy concerns within a domestic network. Additional research may also provide insight into the barriers to the use of current technologies, such as video chat, to better integrate these tools in a manner that would overcome technical concerns with set up. My research contributions presented in this thesis will be able to inform the design and development of high fidelity prototype systems aimed at providing patients, caregivers, and family members with the means to manage health information and to support the sharing of such information with distributed family members and friends. Families currently coping with the ongoing treatment of a chronic illness should then use a prototype system in their homes for a determined period of time. Researchers could then evaluate their usage, allowing us to learn what features work well for families and where designs can continue to improve.

7.4. Final Words

The issues presented in this thesis impact a large portion of the population. With the aging population in Canada, chronic illnesses are now impacting more families.
Pharmaceutical and technology companies have an interest in developing mobile technologies that support patient care, as seen with the recent initiative of a mobile PHR system between MiHealth Global Systems and Merck Canada (Glauser, 2011, Gullo, 2011) and Telus’ offering of Microsoft’s HealthVault for Canadians (Canadian Healthcare Technology, 2012). However, such systems place emphasis on the management of medical records with less regard to communication channels needed to support patients during times of a health crisis.

With the exponential growth in communication technologies over the last century and the resulting affordability for people to stay connected, a larger number of family members are choosing to become separated over distance for work or school purposes. When a loved one is diagnosed with a chronic illness, the importance of connecting members across varying generations is especially critical during such times. By detailing the ways in which family members share health information within their sharing network, my thesis provides international and Canadian technology companies with a better understanding of the impacts of communication technologies within a domestic environment, specifically in the context of the diagnosis and treatment of chronic illnesses. From there, such companies may now refer to the findings presented in this thesis to inform the design and development of new technologies to support the sharing of health information.
References


Appendices
Appendix A.

Recruitment Poster

Are you or a family member coping with a chronic illness?

SFU researchers are seeking participants for a study that explores how family members communicate information during a health crisis.

The goal of this study is to understand how remote family members try to maintain an awareness of patients’ changing health conditions while providing social support from a distance.

By evaluating preferred methods of communication between patients, caregivers and family members, this study will inform the design of a health-sharing system that supports feelings of human connectedness.

Ideal participants will:
1. Have a family member (or been a patient) with an illness within the past 5 years
2. Be living remotely from family members (different homes, cities, and/or countries)
3. Have experience with basic technology (telephone, computer, …)
4. Use some form of online communication (email, instant messaging, Facebook, …)

Your participation will include:
1. Brief questionnaire
2. Private 1-hour interview to discuss your communication patterns

You will be compensated $50 and all information collected will remain anonymized.

To participate in this study, please contact:
Carolyn Pang (carolyn_pang@sfu.ca)
Dr. Carmen Neusyeder (carmen_neusyeder@sfu.ca)
Appendix B.

Email Qualifier

Hi <name>,

Thank you for your interest in the study. We need to recruit particular demographics for the study; to ensure you meet our requirements, could I ask you to briefly answer these questions? Once I hear back, I will let you know how to proceed.

- Please identify the chronic illness the family is coping/has coped with.
- When was the illness diagnosed?
- Which city do you live in?
- Where does the patient live?
- Where do your family members live?
- Do you share or receive any health information related to the patient?
- What is your relationship to the patient?

Data is kept completely anonymous and this is explained in our consent form; please review this document closely before agreeing to participate in the study: http://clab.iat.sfu.ca/health. Also note that the diary study is optional and we will only be asking certain individuals.

If you have questions or concerns please feel free to contact me at carolyn_pang@sfu.ca.

Warm regards,
Carolyn
Appendix C.

Study Protocol

*Introduce yourself and tell them about the study.*

My name is Carolyn, and I will be conducting the study with you and will answer your questions.

We are investigating how family members who live in different households try to maintain an awareness of patients' changing health conditions while providing social support from a distance. Our interest is in how you communicate with family members, which tools you use and how you feel after each conversation. We are also interested in understanding the type of health information you share or receive within your social networks.

For your participation in the study, you receive $30.

*Tell them about the study method.*

The study will involve a *semi-structured interview* where I will ask you questions about your household, your family, the illness, and communication tools. I will also get you to answer a questionnaire.

*Tell them about data collection.*

I'm going to be collecting data using a variety of methods. I'll take handwritten notes and also audio-record the interview, if that is fine with you. Also, if it is okay, I’d like to take pictures of some sketches I'll ask you to make, and any calendars you use.

*Let them know it’s okay to quit if they are uncomfortable about anything you ask.*

While I don’t foresee any issues, if you should feel uncomfortable at any time, you are free to quit the study without repercussions. Just let me know.

*Give them the consent form.*

**IN PERSON**

I now need you to read over this consent form, a copy of which is given to you, and let me know if you have any questions. The form mostly details what I have just told you. Once you have read it, you can sign the back.

**VIDEO CONFERENCE**

Have you had a chance to review the online informed consent form I sent you the link to? Thank you.

**IN PERSON**

So I don’t forget later on, I’m going to pay you now and have you sign this receipt. The receipt allows us to get reimbursed for the money.

**VIDEO CONFERENCE**

So I don’t forget later on, could I ask for your mailing address so I can send you a cheque. Could you please send me an email once you receive this to confirm that you’ve received payment?

*Start the study.*

Alright, we are all set to start the study. I’m going to turn on the audio recorder at this time.
Appendix D.

Consent Form

Research Project Title:
The Role of Communication and Technology for Families Coping with Chronic Illnesses

Ethics Application Number: 2012s0086

Investigators:
Carolyn Pang, SIAT, Simon Fraser University carolyn_pang@sfu.ca
Carman Neustaedter, SIAT, Simon Fraser University carman_neustaedter@sfu.ca
Serena Hillman, SIAT, Simon Fraser University shillman@sfu.ca
Erick Oduor, SIAT, Simon Fraser University eoduor@sfu.ca

The Simon Fraser University Research Ethics Board has approved this research study.

This consent form, a copy of which is made available to you, is part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask the investigator(s). Please take the time to read this carefully and to understand the information.

Purpose:
The purpose of this research is to understand the information families coping with chronic illnesses wish to share with and receive from remote family members. This includes studying the communication patterns of patients, caregivers, and family members and the methods in which they present their availability. We will use this knowledge to inform the design of a health information sharing system that supports feelings of connectedness during a family health crisis.

Participant Recruitment and Selection:
To be recruited for this study, you should be comfortable talking about your daily routine, technology usage, and thoughts about your current interactions with your remote family. Because the focus is on sharing health information, you should also be comfortable talking about your current health status and/or conditions and any details related to your medical treatments.

What Will I Be Asked To Do?
Through an interview and/or diary study, we will ask you questions about: your general health and family history, your communication patterns and relationships with your remote family members, your preferred methods of contacts and sense of awareness, social presence and closeness.

Your Participation
You will be paid $30 for participating in the interview and/or $20 for completing a diary. The interview will take approximately 1-2 hours of your time; the diary will be logged for 3-5 weeks. If you agree to participate, you will be free to withdraw at any time for any reason. However, data collected up to that withdrawal point may still be retained and used by the researchers. Should you decide to withdraw before completion, the payment will be reduced by pro-rating it to the time actually spent.
Research results, such as published papers, can be obtained by contacting any of the investigators:

Carolyn Pang  carolyn_pang@sfu.ca
Carman Neustaedter  carman_neustaedter@sfu.ca
Serena Hillman  shillman@sfu.ca
Erick Oduor  eoduor@sfu.ca

What Type of Personal Information Will Be Collected?

Your anonymity will be strictly maintained. The only personally identifying information collected will be your name, which will only be used for administration of payment. Any data collected will be labelled with an anonymous participant ID. We will also be using video, audio, and photographs to record portions of your interview in order to aid our data analysis. Participants will remain anonymous, but researchers will refer to participants (if at all) by a pseudonym in all video, audio and photographs; any identifying pieces of information will be blurred.

Are There Risks or Benefits if I Participate?

The risks of participation are intended to be none or minimal. However, because we will be asking you personal questions, there is risk of feelings of emotional discomfort such as embarrassment, and/or concerns about privacy. To mitigate this, you can choose what information you are comfortable revealing.

What Happens to the Information I Provide?

No one except the researchers and their assistants will be allowed to see or hear any of the answers to the questionnaire or the interview tape. All electronic data and questionnaires collected as part of the study will be kept on an external hard drive and stored in a locked cabinet in the secure office of the primary investigator at the School of Interactive Arts and Technology (SFU Surrey Room 3930) until 2015.

We expect to publish reports and presentations describing this research. Public presentations of the results will primarily present the results in an aggregate form or as caricatures that are composites of one or more participants. Where individual participant data is disclosed, such as exemplar interview comments or quotes, we will ensure that the selected data does not suggest participant identities.

As stated above, we will also be using video, audio, and photographs to record portions of your interview to aid our data analysis. These may be used within publications or presentations of our research.
Acceptance of this Form:

Your signature on this form indicates that you 1) understand to your satisfaction the information provided to you about your participation in this research project, and 2) agree to participate as a research subject.

In no way does this waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from this research project at any time. You should feel free to ask for clarification or new information throughout your participation.

Participant's Name (please print):

_____________________________________________

Participant's Signature:

_____________________________________________

Date: ______________

Questions/Concerns:

If you have any concerns about the way you’ve been treated as a participant or concerns with the research project, please contact (primary) Dr. Carman Neustaedter, Assistant Professor, School of Interactive Arts and Technology at: carman_neustaedter@sfu.ca or (secondary) Dr. Hal Weinberg, Director, Office of Research at: hal_weinberg@sfu.ca.
Appendix E.

Interview Questions

Section 1: Family and Social Map (demonstrate social groups)

Please draw a picture or map that shows how you are connected with all the people who you communicate with about <patient>’s condition. Try starting by writing your name down and drawing a circle for you. Then draw some other people. You can draw them anywhere, but think about where you place them in relation to yourself.

1. Tell me about your drawing, who are these people and why did you draw the map the way you did?
2. Confirm number of people in the group.
3. How many people live in your household and what are their ages?
4. How many members live(d) with the patient and what are their ages?
5. Can you think of an instance when you shared with someone outside of this group? Why do you think you shared with them but did not include them on this map?
6. Who do you share with the most in this group? Where do these people live? Why do you think you communicate most with this group?
7. Who do you share with the least in this group? Where do these people live? Why do you think you communicate least with this group?

Section 2: Health information

8. What role do/did you have in this health crisis? (caregiver/communicator, recipient)
9. Tell me how you felt when you first received news about <health condition>.
   ○ Do you remember the first person you contacted? How did you contact them?
   ○ Describe some of the activities you did in the first month following the diagnosis.
   ○ Have you sought help online from any support groups? Which ones?
   ○ Looking at your family map, describe the types of health information you currently share/receive with certain individuals.
10. Tell me about how you share health related information with <group from map>. What type of information do you share and how do you share it?
11. Tell me about the most difficult time you shared health related information? Who was it with and how did you share it? How did you feel afterwards? The diagnosis day. It was shared by telephone. It relieved the burden. It also felt horrible because we were just diagnosed, but it helped.
12. Describe some ways that your family members/friends have helped during this time.
13. Describe a particular moment in which you felt someone was especially helpful/considerate. Why?
14. Describe a time when you felt helpless and unsupported by a family member.
15. Describe a time when you felt you should've supported a patient but didn't. What are some of the barriers you faced in offering help?
16. Describe how you coordinate/manage household activities and tasks. Which tools do you use?
17. Has the health condition impacted your schedule in any way? Tell me more. Explain how your time management behaviour changed since the diagnosis, if at all.
Section 3: Technology use (understand proficiency in existing tools)

18. Do you currently use email to share health information? Do you have a separate email account specifically for this purpose?
19. Which social media accounts do you have set up, if any? (Skype, Twitter, Facebook, Tumblr, Flickr, etc.) Describe how often you use these accounts (list frequency for each one). Do you use any of these to share health information? Why (or why not)?
20. Of all the communication methods available to you, identify the tool you prefer to use in receiving/sharing health information? Why?
21. Describe any frustrations you have with technology as it relates to sharing/receiving health information.
22. Do you have any concerns with privacy issues with online tools such as email or social media? Explain.
23. Do you have any concerns with privacy issues offline, for example, in doctor’s offices or how people you share health information with might handle what you share? Explain.
24. Can you recall a time when you felt your trust in someone was compromised because they shared health information you confided in them?

Section 4: Sketch designs (ideas that show important health information management)

25. Think for a moment about some common web pages, systems or devices you access (can be smartphones, computers, tablets, digital picture frames, eReaders, etc.). Now I’ll ask you to draw a sketch of a single screen dedicated to sharing health information about <patient>. List or draw any items you’d like to see or tools that you would use to facilitate communication within your map.

Section 5: Evaluate the following designs (show snapshot of 1-2 pages with main functionality for each of the 5 listed above)

26. Are you familiar with the following sites that provide families with tools to help during a health illness?
   - LotsaHelpingHands (http://www.lotsahelpinghands.com/)
   - Patientslikeme (http://www.patientslikeme.com/)
   - CaringBridge (http://www.caringbridge.org/)
   - Microsoft HealthVault (http://www.microsoft.com/en-us/healthvault/)
   - Telus HealthSpace (http://telushealthspace.com/)
27. Circle what you like in green and what you don’t like in red. Feel free to mark it up in any way, cross things out, make notes. [THIS WILL BE DIFFERENT FOR VIDEO CONFERENCE]
28. What stands out most to you? What is your first impression?
29. What don’t you like about it?
Appendix F.

Data Analysis

The following is a comprehensive list of codes generated during the open, selective, and axial stages of data analysis.

### Tools Used to Communicate

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>[E]</td>
<td>Email</td>
</tr>
<tr>
<td>[FB]</td>
<td>Facebook</td>
</tr>
<tr>
<td>[FBIM]</td>
<td>Facebook instant messaging</td>
</tr>
<tr>
<td>[GTALK]</td>
<td>Google chat instant messaging</td>
</tr>
<tr>
<td>[MAIL]</td>
<td>Mail</td>
</tr>
<tr>
<td>[MSN]</td>
<td>MSN messenger instant messaging</td>
</tr>
<tr>
<td>[P]</td>
<td>Phone</td>
</tr>
<tr>
<td>[S]</td>
<td>Skype</td>
</tr>
<tr>
<td>[TXT]</td>
<td>Text</td>
</tr>
<tr>
<td>[VC]</td>
<td>Video chat</td>
</tr>
</tbody>
</table>

### Reasons for Choosing Certain Tools to Communicate

<table>
<thead>
<tr>
<th>Code</th>
<th>Reason</th>
</tr>
</thead>
<tbody>
<tr>
<td>[CLOSE]</td>
<td>Feelings of closeness</td>
</tr>
<tr>
<td>[CONV]</td>
<td>Convenience based on schedules</td>
</tr>
<tr>
<td>[PORT]</td>
<td>Portability</td>
</tr>
<tr>
<td>[SKILL]</td>
<td>Technological skill levels</td>
</tr>
</tbody>
</table>

### Tools Used to Manage Records

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>[CAL-ELEC]</td>
<td>Calendar – electronic (e.g. Google Calendar, Outlook, phone)</td>
</tr>
<tr>
<td>[CAL-PPR]</td>
<td>Calendar – paper-based</td>
</tr>
<tr>
<td>[FILE]</td>
<td>Files and folders</td>
</tr>
<tr>
<td>[NOTE-ELEC]</td>
<td>Notepad – electronic (e.g. computer, phone)</td>
</tr>
<tr>
<td>[NOTE-PPR]</td>
<td>Notepad – paper-based</td>
</tr>
<tr>
<td>[OUTLOOK]</td>
<td>Microsoft Outlook features (e.g. tasks)</td>
</tr>
<tr>
<td>[PHONE]</td>
<td>Smartphone</td>
</tr>
<tr>
<td>[POST-IT]</td>
<td>Physical post-it notes</td>
</tr>
</tbody>
</table>

### Health Information Shared

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>[APPT]</td>
<td>Medical appointments</td>
</tr>
<tr>
<td>[FUND]</td>
<td>Fundraiser events</td>
</tr>
<tr>
<td>[INFO]</td>
<td>Information about the illness</td>
</tr>
<tr>
<td>[LINK]</td>
<td>Links to online resources about the illness</td>
</tr>
<tr>
<td>[MED]</td>
<td>Medications</td>
</tr>
<tr>
<td>[MOOD]</td>
<td>Different moods (e.g., angry, reserved, quiet, grumpy)</td>
</tr>
<tr>
<td>[PAIN]</td>
<td>Degrees of pain</td>
</tr>
<tr>
<td>[PHOTO]</td>
<td>Photos</td>
</tr>
<tr>
<td>[SIDE]</td>
<td>Side effects</td>
</tr>
<tr>
<td>[SYPTM]</td>
<td>Symptoms</td>
</tr>
<tr>
<td>[TEST]</td>
<td>Test results</td>
</tr>
<tr>
<td>[TRTMT]</td>
<td>Treatment lifecycles, plans</td>
</tr>
</tbody>
</table>
### Individuals in Health Sharing Network

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>CFRD</td>
<td>Close friend, best friend</td>
</tr>
<tr>
<td>CHUR</td>
<td>Church</td>
</tr>
<tr>
<td>EXTFA</td>
<td>Extended family</td>
</tr>
<tr>
<td>FAM</td>
<td>Family, In-laws</td>
</tr>
<tr>
<td>FRD</td>
<td>Friend</td>
</tr>
<tr>
<td>MED</td>
<td>Medical professional, nurse, doctor, specialist</td>
</tr>
<tr>
<td>PARENT</td>
<td>Parent, step-parent</td>
</tr>
<tr>
<td>PEER</td>
<td>Peers, fellow students, group mates</td>
</tr>
<tr>
<td>SIBLING</td>
<td>Brother, brother-in-law, sister, sister-in-law</td>
</tr>
<tr>
<td>SPVR</td>
<td>Work supervisor, school supervisor</td>
</tr>
<tr>
<td>STRAN</td>
<td>Stranger</td>
</tr>
<tr>
<td>WORK</td>
<td>Work colleagues</td>
</tr>
</tbody>
</table>

### Desired Features Identified during Design Activity

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>F-ADDRESS</td>
<td>Contact information, including address of medical facilities</td>
</tr>
<tr>
<td>F-ADMIN</td>
<td>Ability to provide secure administrator privileges</td>
</tr>
<tr>
<td>F-AVAIL</td>
<td>Availability indicator</td>
</tr>
<tr>
<td>F-CAL</td>
<td>Calendar</td>
</tr>
<tr>
<td>F-CONNECT</td>
<td>Ways to connect with other patients</td>
</tr>
<tr>
<td>F-CONTACT</td>
<td>Contact list of key people</td>
</tr>
<tr>
<td>F-IM</td>
<td>Instant messaging capability</td>
</tr>
<tr>
<td>F-INFO</td>
<td>Access to online, credible information about the illness</td>
</tr>
<tr>
<td>F-NOTE</td>
<td>Ways to write, store, and share notes</td>
</tr>
<tr>
<td>F-PHONE</td>
<td>Phone capability</td>
</tr>
<tr>
<td>F-SOCIAL</td>
<td>Social media integration options</td>
</tr>
<tr>
<td>F-STATUS</td>
<td>Ways to share health status</td>
</tr>
<tr>
<td>F-SUPPT</td>
<td>Ways to care and provide support for a patient</td>
</tr>
<tr>
<td>F-TEXT</td>
<td>Text capability</td>
</tr>
<tr>
<td>F-TREAT</td>
<td>Stages of treatment</td>
</tr>
<tr>
<td>F-VIDEO</td>
<td>Video chat capability</td>
</tr>
</tbody>
</table>

### Undesirable [N-*] Features Identified during Summative Evaluations

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>N-CHART</td>
<td>Dislike – charts and graphs</td>
</tr>
<tr>
<td>N-CMPY</td>
<td>Dislike – company and industry partners</td>
</tr>
<tr>
<td>N-COLOUR</td>
<td>Dislike – design colours</td>
</tr>
<tr>
<td>N-DONATION</td>
<td>Dislike – solicitation of donations</td>
</tr>
<tr>
<td>N-JOURNAL</td>
<td>Dislike – online journal ability</td>
</tr>
<tr>
<td>N-NAME</td>
<td>Dislike – name of system and/or logo</td>
</tr>
<tr>
<td>N-MSCFT</td>
<td>Dislike – Microsoft</td>
</tr>
<tr>
<td>N-ORGZ</td>
<td>Dislike – organization</td>
</tr>
<tr>
<td>N-PHOTO</td>
<td>Dislike – photo sharing capability</td>
</tr>
<tr>
<td>N-SOCIAL</td>
<td>Dislike – integration with social media (e.g. Facebook, Twitter, YouTube)</td>
</tr>
<tr>
<td>N-VIDEO</td>
<td>Dislike – embedded videos</td>
</tr>
<tr>
<td>Feature</td>
<td>Description</td>
</tr>
<tr>
<td>-----------</td>
<td>-----------------------------------------------------------------------------</td>
</tr>
<tr>
<td>[Y-CHART]</td>
<td>Like – charts and graphs</td>
</tr>
<tr>
<td>[Y-COLOUR]</td>
<td>Like – design colours</td>
</tr>
<tr>
<td>[Y-CONTACT]</td>
<td>Like – contact list of medical facilities</td>
</tr>
<tr>
<td>[Y-FORUM]</td>
<td>Like – online forums and community support</td>
</tr>
<tr>
<td>[Y-PHOTO]</td>
<td>Like – photo sharing capability</td>
</tr>
<tr>
<td>[Y-JOURNAL]</td>
<td>Like – online journal ability</td>
</tr>
<tr>
<td>[Y-ORGZ]</td>
<td>Like – organization</td>
</tr>
<tr>
<td>[Y-SEARCH]</td>
<td>Like – search functionality</td>
</tr>
<tr>
<td>[Y-SOCIAL]</td>
<td>Like – integration with social media (e.g. Facebook, Twitter, YouTube)</td>
</tr>
<tr>
<td>[Y-VIDEO]</td>
<td>Like – embedded videos</td>
</tr>
</tbody>
</table>
Appendix G.

Participant Health Information Sharing Maps

P1
My Mom

My Sister

(Husband) at the time

(me)

My Dad

Family in Poland

A

A

(closest friends)

Other

Friends

Co-workers and clients (work)

most communication

least communication

Gramma

Cousins

Dad

Uncle

Aunt

other relatives

M6

siblings

Parents

Close Friends

Other Social Network