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Technology Preferences and Routines for Sharing Health Information during the Treatment of a Chronic Illness

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ABSTRACT

When a patient has a chronic illness, such as heart disease or cancer, it can be challenging for distributed family members to stay aware of the patient's health status. A variety of technologies are available to support health information sharing (e.g., phone, video chat, social media), yet 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 explore this, we conducted a mixed-method study—involving a survey and in-depth interviews—with people about their health information sharing routines and preferences for different technologies. 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. With family members adopting certain roles during the treatment of chronic illnesses, our findings suggest the need to design tools that mediate sharing health information across distance and age gaps, with consideration to respecting patient privacy while sharing health information.

Author Keywords

Health informatics, families, social support, communication

ACM Classification Keywords

H5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

INTRODUCTION

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 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 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'. We also see a variety of new online tools being created that focus specifically on health information sharing (e.g., LotsaHelpingHands, CaringBridge).

Anecdotally we know that the above technologies are used for sharing health information while a family member has a chronic illness. Yet 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 [22] 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.

Given this, our paper presents findings from a mixed-method study—containing both quantitative and qualitative components—focused on understanding how and why family members choose particular technologies for sharing health information about a loved one suffering from a chronic illness. First, we use a survey to explore the affective benefits and costs of synchronous and asynchronous communication tools for health information sharing. Our results highlight that the phone provides the most communication benefits, yet most technologies do not differ in terms of their associated communication costs.

Second, we dive more deeply into family members' communication routines through in-depth interviews. Our results illustrate more deeply the reasons why people choose certain technologies over others, the ways in which they use them, and the challenges they face (or do not). Specifically, we found that people have a preference for using technologies most similar to face-to-face situations; yet video chat still presents limitations that make it difficult and sometimes undesirable to be used. Asynchronous communication tools support sharing information when people have less time to share in-the-moment. They also support sharing with weak ties, despite the sensitive nature of some health information. We also saw that some family members filter health information, shielding younger generations from having a full awareness of the situation.

In this paper, we first summarize related work on health information sharing. We then present the quantitative component of our study, followed by the qualitative component. Finally, we conclude with a discussion outlining design implications for future health information sharing systems.

RELATED WORK

Health Information Management
Patients with chronic illnesses often rely on family members and friends for support as they cope with a flood of new health information and resources. Pratt et al. [19] found that breast cancer patients have health information and records distributed in various forms, such as paper, email, and web references; however, people do not necessarily know what to do with all the information received, often forgetting to use it or becoming overwhelmed because of the language and volume. Cancer patients also expressed the desire to share details of their health information, such as appointments and health updates, with others in their social network, but were frustrated with the limitations in exchanging information in 'semi-public work settings', such as over the telephone while at work [19].

Klasnja et al. [12] 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. Personal health record (PHR) systems, such as Google Health and Microsoft HealthVault, may assist patients with this, but studies have revealed a number of barriers to the adoption of these tools, including concerns with privacy (the possibility of sharing too much information), ease of use, and accessibility [13,24].

Social Support for Patients
A number of studies have been conducted to understand the role that social networks play in supporting patients. Civan et al. [4] focused on how people 'source' or find health information expertise (e.g., finding disease information, a registered nurse, or someone who has previously had the disease). Their study found that people are careful not to burden family or friends with their health issues and only identify select individuals (gatekeepers) in their social network whom they rely on to help with expertise sourcing. Civan et al. defined three such gatekeeper roles: a *conduit* was responsible for funneling information to the patient and acting as a point of contact to pass messages from the patient to an external source; a *contact broker* would introduce participants to sources of expertise outside their support community; and, a *champion* was often a key source of expertise with a breadth of knowledge that crossed multiple domains (e.g., a registered nurse) [4]. Skeels et al. [22] studied the ways in which family members support patients and found that two distinct roles exist: *proxy* and *coordinator*. A *proxy* is someone whom patients trust to interact with their social network on their behalf, including setting up a profile within an online sharing

system, inviting people to a 'helping network', and deflecting unwanted offers of help [21]. Often times, a spouse or parent assumes this role. A *coordinator* is someone who manages one piece of the support network, and has limited access to information, typically assisting proxies with specific tasks, such as arranging transportation or meals [21].

Health Information Sharing
Turning to our focus on the actual sharing of health information, Moncur [15] and Skeels [22] outline the types of information people share during serious and non-serious health situations. First, we learn that the most commonly shared information was about treatments, diagnosis, symptoms, likely long-term impacts, experiences with doctors, and stories of similar situations [22]. Such sharing was meant to provide help, encouragement, support, and sympathy, and also to relieve anxiety [15,22]. This emphasizes the importance of facilitating social support across distributed households. Sometimes patients are not comfortable sharing all the information and will hold back because information may be too personal or they may not want to worry people [15,22]. For example, Benjamin et al. observed how seniors with chronic pain carefully managed their interactions with others to maintain a certain level of self-presentation [1].

Skeels [22] also provides an ordered list of which technologies were used most frequently to share health information. Here we see that the most commonly used method was talking in person, followed by talking over the phone. Email was identified as the third most common technology, followed by physical letters, instant messaging, and faxing. The above list is certainly beneficial, yet we do not learn about rationale behind this usage, the ways in which the technologies are used, and what challenges (if any) people face using them. This is where our work picks up as it explores the nuances of technology selection and usage.

Family Communication and Identity
Stepping back, it is also important to understand how families communicate in situations without health concerns. This provides an important foundation for comparing health situations to non-health situations. First, studies have focused on family communication for geographically-distributed members [2,3]. Here we see that synchronous communication tools (e.g., phone, video chat) are often preferred for emotional-based conversations, while asynchronous methods are ideal for coordinating schedules [2,3]. People also choose the technology that is most familiar to them and that they are likely to reach the remote person with [17,25]. Heavy computer users favor email [17,25], while video chat systems are often used to avoid long distance phone charges [17,25]. There is also a preference to 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 [10]. More generally, we know that people prefer in-the-moment sharing of information where sharing is

targeted [20]. In contrast, they dislike feeling obligated to send information [7,20]. Despite these 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 our paper.

QUANTITATIVE STUDY METHODOLOGY

We investigated health information sharing through a mixed-methods quantitative and qualitative study focused on the perspective of family members of patients with a chronic illness. Prior work has often studied patient behaviors and needs; by focusing our study on family members, we sought to analyze a broader sample that is representative of a patient's social network. This perspective is especially important in understanding how loved ones want to stay aware of and assist patients.

In this first section, we document the quantitative study and its results. Later, we document the qualitative study and its findings, which dive more deeply into possible explanations for the results from the first study.

Participants

To represent the broad scope of a family network, we sought participants diverse in age, education, profession, and illness. 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. All participants resided in North America and their family members were located globally, living in North America, Europe, Asia, and Australia. All 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. 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. Participants were diverse in their socioeconomic status with professions falling in academic and public sector industries. All participants had experience with basic technology, such as the telephone and computer, and online communication, such as email and Facebook.

Questionnaire

Participants completed the validated Affective Benefits and Costs Questionnaire (ABC-Q) [8,26] to quantitatively compare the affective benefits and costs of synchronous and asynchronous communication technologies during situations of chronic health illnesses. The questionnaire asks users to rate technologies focused on benefits (emotional expressiveness, engagement, presence-in-absence, and social support) and costs (obligations, unmet expectations, and threats to privacy) for communication. 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. This allowed us to evaluate widely adopted and familiar tools (telephone and email) while also considering technologies that have seen a recent uptake in usage by families (video chat [10] and Facebook [18]). Two participants' responses to the questionnaire were incomplete and thus omitted during our analysis.

Participants were asked to answer 26 questions for each of the four communication tools (104 questions total), focusing 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 1 shows sample questions for 'Benefits' and 'Costs.' 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 = Rarely, 5 = Always).

Benefits	
Emotional expressiveness	Communicating with [P] using [M] helps me tell how [P] is feeling that day.
Engagement and playfulness	I have fun with [P] while using [M].
Presence-in-absence	Communicating with [P] using [M] helps me feel more connected to [P].
Opportunity for social support	Communicating with me using [M] helps [P] be there for me when I need them.
Costs	
Feeling obligations	I worry that [P] feels obligated to contact me using [M].
Unmet expectations	I feel sad when [P] isn't around when I try to contact [P] using [M].
Threat to privacy	I worry that others may overhear or see something that [P] and I share using [M].

Table 1: Sample of questions where [P] = Person and [M] = Method of Communication

Hypotheses

Based on the previous literature, we can see that people valued both synchronous and asynchronous communication technologies for different reasons and in varying situations. 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.

RESULTS

Affective Communication Benefits

Most participants reported high affective benefits of using the telephone to communicate health information (mean = 3.9, SD = 0.8, across all twelve 'benefit' questions). The second method of communication that yielded high affective 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 1).
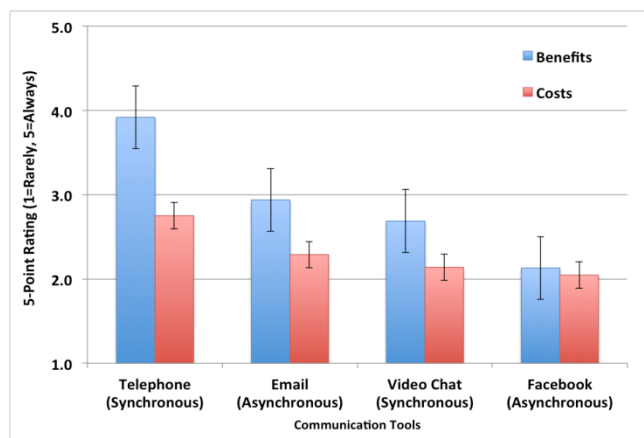

Figure 1: Ranked benefits and costs across technologies with error bars indicating standard error of the mean

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 across all possible communication medium pairs were performed to test hypothesis (H1) that the benefits for synchronous methods of communication would be higher than each asynchronous method. 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 or Facebook. That is, while the synchronous communication method (telephone) showed higher benefits than any of the asynchronous communication methods (email and Facebook), thus confirming H1, the synchronous communication method video chat did not show any such benefit. Hence, H1 was rejected for video chat.

Affective Communication Costs

We also performed a one-way repeated-measure ANOVA to evaluate the effect of communication tool on affective costs. This showed no significant difference; therefore, we rejected our second hypothesis. This shows the tools do not have different affective costs associated with communication.

Sub-categories of ABC Questionnaire

Figure 2 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.

We conducted a one-way repeated-measure ANOVA on each grouping of benefits. 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).

We also ran a one-way repeated-measure ANOVA on each grouping of costs and only noted a significant difference for 'feeling obligations'. 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.

Summary

Overall, our 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 video chat did not appear to provide more affective benefits than the asynchronous methods, despite previous studies showing people use it to provide emotional closeness over distance [10].

We explore the reasons behind this more in our subsequent qualitative portion of the study. 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 also explore this in the subsequent study component.

QUALITATIVE STUDY METHODOLOGY

We conducted a second stage in the study where we had the same set of 17 participants complete two qualitative activities: a paper-based task and an in-depth interview. The goal was to more deeply explore how and why people used each form of technology for health information sharing.
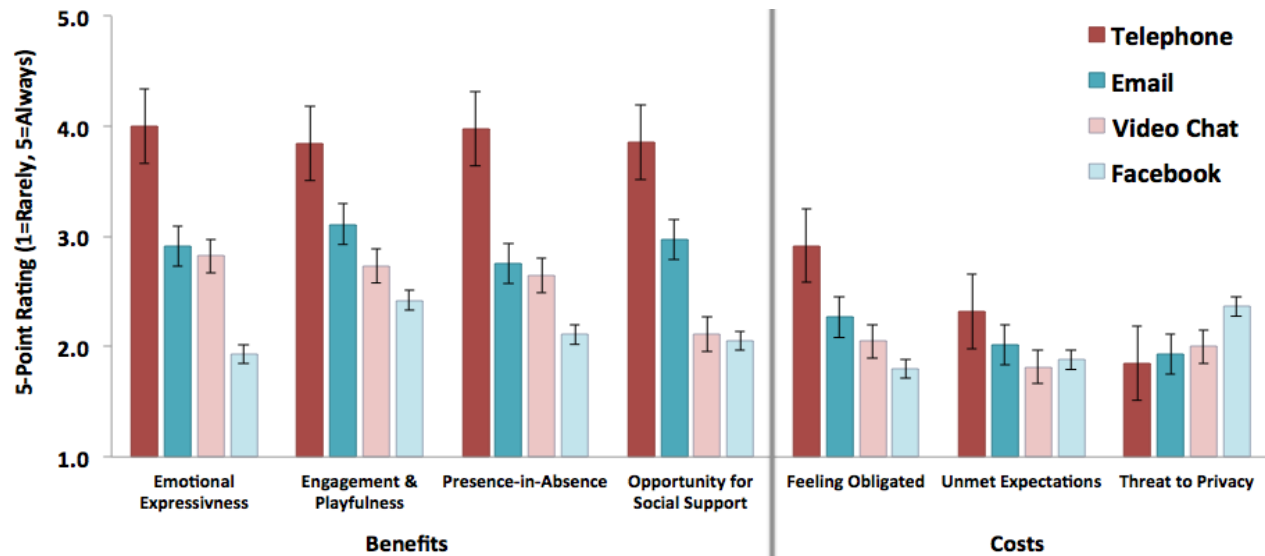
Figure 2: Analysis of mean benefits and costs across technologies with error bars indicating standard error of the mean

Paper-Based Task

The first paper-based task looked at who family members included in their health sharing network while patients underwent treatment. Adopting a method used in prior studies to understand family communication patterns [25], we provided individual participants with a blank sheet of paper and asked them to draw an illustration that depicted their health information sharing network. We intentionally provided a blank sheet to encourage participants to freely draw and organize their network as they wanted to represent it, giving consideration to the flow of communication and the tools used to communicate health information within their social network. Participants were encouraged to include anyone with whom they shared or received information, as it related to the illness.

Semi-Structured Interviews

We conducted semi-structured interviews, ranging from 90 minutes to three hours, in person with eleven participants and via Skype with six participants, resulting in 132 typed pages of transcribed audio. Participants described their (self-drawn) health information sharing networks, the types of health information shared or received from certain individuals or groups, and the methods in which they communicated. For example, sample questions included, "How do you communicate with this person?", What do you talk about with this person?", and "What do you not talk about?". All interviews were audio-recorded and transcribed.

Data Analysis

Interview data was analyzed using open, axial, and selective coding [23]. During the process of transcribing interviews, we assigned a code to any observation (e.g., [R] for role in health network), and used that code to mark any recurrence of it. We then reviewed each concept to understand their context and causes of behaviors. Finally, we centralized our focus on the core concepts found in our coding.

Our results from this study are described as follows. First, we document the various roles that participants assumed as part of a health information sharing network. Second, we discuss the reliance on certain communication tools to disseminate health information across the support network. Third, we discuss how health information is managed and shared within a support network. Finally, we outline the ways health information was filtered to family members.

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. Participants drew their sharing networks in different ways; some participants listed specific individuals while other participants listed clusters of people (groups of contacts). 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).

Roles within Family Networks

All 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/school supervisors were informed on an 'as-needed' basis (e.g., rescheduling deadlines). Some participants also included medical professionals in their network, depending on the frequency of communication. Our analysis also revealed three communication roles, often 'softly' established based on the distance between family members and the patient.

1. Caregivers are individuals who live with a chronically-ill patient and assist in the ongoing daily treatment of the

illness. Four of our participants were caregivers. Often, a parent of a young child or a spouse assumes this role. Caregivers were privy to much more detailed information about a patient's condition than others. This was attributed 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 channeled 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' [21] *proxy* role, however, ours relates to health information sharing rather than providing social support.

2. Local supporters are individuals who live in a different household but within the same city as the patient. 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. 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' [21] *coordinator* role, often physically stepping in (rather than coordinating) to relieve caregivers of their role by accompanying patients to appointments.

3. Remote supporters 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 health statuses. 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 and to provide emotional support to the patient.

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. We elaborate on this in subsequent sections.

COMMUNICATION TOOL USAGE
Across the various roles, we saw people had different technology preferences with varying reasons.

Preference for Synchronous Technologies
All participants used synchronous methods of communication, such as the telephone, to keep in touch with other family members. 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 was described as secondary in preference to in-person conversations due to convenience, mobility, and cost-effectiveness. 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. 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

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 'costs' listed in the ABC Questionnaire 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

Thus, overall, even though family members wanted to feel close to the individual, which comes from seeing them, 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.

Moving Away from Talking and Face-to-Face

Family members described situations when patients appeared selective about what information was revealed about their condition in order to 'preserve face' and 'maintain positive impressions' [1,11]. 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, P13 is 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. 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 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

Second, and more surprising, we even saw people limit who could see them in person because of their appearance. For example, 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. 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

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.

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 flexibly-timed 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

Online Sites Like Facebook Were Too "Public"
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

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.

Generational Differences
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, they even helped install video chat software but were excluded from video chat sessions 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 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 by excluding his 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." – P13, Male, Age 44

DISCUSSION
Our analysis of technology preferences and health information sharing practices extends prior research to present design opportunities for future systems. We now summarize and discuss our main results.

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. [20] for family communication in general.

Skeels [10] 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. Our study demonstrates that the real-time nature, portability, and ease-of-use of the telephone provides the highest communication benefits for informative communication over distance. 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 might be attributed to the immediacy of synchronous communication. Interestingly, video chat was not rated to have similarly high levels of feeling obligated to connect, despite also being a synchronous communication method. As several participants described, this is because they had to use the phone to schedule a video chat session and there was extra technological effort to set up the video chat software. As the technological barriers of video chat decline, it will be interesting to see if the use of video chat increases or if the feeling of communication obligation will rise.

Participants also described that the timing of information exchange was highly valued, especially for evaluative purposes. Our study revealed that both synchronous and asynchronous technologies were important for family members, depending on the situation. 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. 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. This suggests that when designing communication technologies for health information sharing there is no 'one size fits all' solution.

Communicative acts fall into different types of categories of information exchange, including informative, supportive, and evaluative communication needs. At times people will require technologies such as the phone that allow emotional expression and strong feelings of connection, and, at other times, they will require systems that permit the sharing of sensitive information in an asynchronous nature. In situations where there is need for solitude, asynchronous systems may be most appropriate so that family members can help patients regulate their autonomy and choose when and how they communicate with others. This could be especially important when a patient is critically ill.

Small Networks
Our study also showed that health information sharing networks were typically quite small. Hartzler et al. [6] found that cancer patients reported sharing diagnosis and treatment information with an average of 75-97 people from their social networks. Our 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. We see a similar finding in [17], whose study identified a median number of 13 individuals within an extended social circle (casual relationship). The implication is that health information sharing systems may be best designed for a close-knit circle of family and friends with options to share information with select online communities. Communicating across generations (or not) and

the challenges people had in doing so presents an interesting social question that design may not easily address on its own.

Self-Presentation
Our findings also revealed that participants felt patients were self-conscious of their conditions, often going to great lengths to maintain a certain level of privacy and self-presentation. Benjamin et al. [1] also reported that seniors were selective with the information they shared about their chronic pain, often refraining from revealing pain to reflect themselves positively (impression management) [5]. Skeels [10] echoes these findings with patients revealing far less health information with their immediate families so as to not have them worry. 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. Maintaining a small network helps to mitigate concerns that patients may have with privacy and impression management where family members must be sensitive to the private nature of illnesses.

In the interest of patient privacy, family members also did not want to place too much attention on the patient. We saw that video chat was sometimes seen as being problematic because of patients' concerns over their appearance. Together, this suggests that technologies such as video chat—where feelings of closeness come from seeing another person [8,10]—may not always be an appropriate medium for health information sharing. Instead, systems focused on audio or textual exchanges may be most comfortable amongst family members and patients. If 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 things that they are comfortable revealing.

While we believe our work provides valuable lessons for the design of health information sharing systems, we acknowledge its limitations. 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.

CONCLUSION
Our paper has detailed the ways in which family members share health information within their sharing network. 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. At times, synchronous technologies like video chat could be problematic though and this was important in patients maintaining a preferred identity and appearance. Our results also show that health information is shared with small social networks where certain individuals assume particular communication roles and information may be filtered between generations. This

suggests systems that support sharing between small groups with features that may allow for filtered sharing within the group. Our future work includes looking at the routines we have identified and exploring design possibilities to better support health information sharing amongst families.

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