Title of Study: The Role of Communication and Technology for Families Coping with Chronic Illnesses
Ethics Application Number: 2012s0086
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General Description

The diagnosis of a chronic illness, such as heart disease, stroke or cancer, can be shocking for both the person and their family members. Patients are often faced with new priorities, such as tracking personal medical data, coordinating medical appointments with day-to-day activities and providing family members with an awareness of their health status.

The importance of human connectedness is also especially critical during such times of crisis as patients experience a range of emotions and seek support from their loved ones. In addition to tracking their medical data, patients may struggle with maintaining the privacy of their health information while providing their family with an awareness of their health status. In many cases, a family member may take on a caring role to support the sick person during her ongoing treatment, with an added responsibility of channeling health updates to other family members who may be either co-located within a city or distributed over distance or time. These remote family members also face the challenges of understanding the disease and remaining connected with the patient.

Many studies have evaluated challenges and routines surrounding family communication across distance, noting that time differences and misaligned schedules result in fewer available windows to connect, which then influence feelings of social presence and closeness. This study will specifically explore the information families coping with chronic illnesses wish to share and receive. By studying preferred methods of communication (e.g., email, phone, instant messaging, video conferencing, etc.) between patients coping with a chronic illness and their family members, this study will gather observations that will inform the design of a system that supports feelings of connectedness during a health crisis.

Goals

The overall study goals are to discover:

- The current communication patterns of patients with their remote family members.
- The communication patterns patients adapt to fit their needs given their personal situation.
- The roles caregivers and/or family members play in the communication process.
- The methods patients employ to present their windows of availability for communication with remote family members.
- The ways patients use social media (such as Facebook or online forums) to communicate with their remote family members.

Recruitment

Participants will be recruited via several strategies:

- *Snowball sampling:* Participants will be recruited via family, friends, and colleagues. This will involve people forwarding on our advertisement to others they know who might be interested. Our contact information will be included should interested candidates want to participate.

- *Emails:* Specific target groups will be contacted, such as the grad student mailing list, in accordance with the guidelines within the department, and only after explicit approval from the list coordinators.
- *Social media:* Posts to Facebook, Twitter, Google+ and Craigslist.
- *Posters:* Posters will be placed around campus and in other public areas.

Please refer to **Sample Recruitment Content** for details.

We will recruit interested adult participants who:

- Do not have any major physical (i.e., immobility) or cognitive disabilities (i.e., diagnosis of a mental disability).
- Live remotely from family members. This may include living in different homes, living in different cities, or living in different countries.
- Have a family member (or been a patient) who has been diagnosed with a chronic illness within the past five years.
- Have experience with basic technology (telephone, computer, etc.).
- Use some kind of online communication method periodically (email, instant messaging, social media, video conferencing).

Location of Study

This study will be conducted at places convenient to the participant. This may include visits by the researchers to participants' homes, or discussions at a mutually agreeable meeting place, discussions over the telephone or other real time communication channel (e.g., Skype), and/or electronic interviews via online surveys, email, and/or other asynchronous communication channels.

Researchers will provide participants with a link to the online surveys and conduct interviews at the homes of the participants. Consent for participation via the online survey will take place online where participants will be presented with the consent form, asked to read it, and then acknowledge their acceptance of it by selecting an 'agree' checkbox on the online form.

If we are unable to physically meet with a participant who wishes to participate in the interview/diary study and they participate over another communication channel (e.g., Skype, email), we will send them the consent form electronically, have them read it, sign it, and send it back to us. Confidentiality of information transmitted electronically cannot be assured. For example, Skype encrypts video and audio data being transmitted over the Internet using Secure Socket Layers, but there are still possibilities of risk associated with using such a medium. Participants will then have the option to participate (or not) over such mediums.

Please refer to the **Consent Forms** for details.

Methods

We will use a combination of methods to understand our participants' communication patterns, routines and lifestyles, including online surveys, interviews, and diary studies.

- **Online Surveys:** Participants will be asked to complete an online survey stored on a secure SFU web server. This web page will first contain an online consent form that participants will be asked to read and agree to prior to continuing (see attached consent form). This survey will ask general and targeted questions, such as demographics, health diagnosis, family history, and existing methods of communication. This will help us get to know the participants and understand their behaviours and practices.

- **Interviews:** We will conduct semi-structured interviews with participants, either in their homes or via Skype, Google Chat, or MSN Messenger, where we will have questions prepared, and participants will be given the opportunity to expand and converse with us about related topics. Participants will begin by answering some general health and family history questions so the researchers can understand their current health status and conditions. We will continue with questions about their communication and interaction patterns to better understand their everyday routines and relationships with others.

  Once they have had the chance to answer these basic questions and get comfortable with the researchers, we will move on to questions relating to their attitudes about communication, which will include questions about their preferred methods of communication with their families, including the frequency of contacts and measurements of awareness, social presence and closeness. We will also ask questions about their perceptions and usage of technology and social media.

- **Diary Studies:** Participants will be asked to keep an online diary of their emotions, thoughts and preferred communication methods over a period of approximately three to five weeks. The online diary will be placed on a secure server residing at the SFU Surrey campus. Within the diary, participants will be given a list of questions to answer along with space to add additional comments. This log should include, but is not limited to, descriptions of: whom they spoke with, a general overview of what they spoke about, how they felt before the conversation, and how they felt after the conversation. Diary entries will help us understand the levels of emotional connectedness participants feel and the factors behind these levels.

Remuneration
Participants in the online survey will not be compensated. Each participant in an interview will be compensated with a payment of $30. Each participant in the diary studies will be compensated with a payment of $20. Participants who decide to withdraw before completion will receive an amount pro-rated according to the time actually spent.

Benefits and Risks
Participants will not benefit directly by participating in the study, though they will be compensated for their time according to the remuneration outlined above. The risks of the study are expected to be none or minimal. Some of the questions we ask are personal in nature, as they ask people to divulge details of their lifestyles. Though many of the questions are about mundane lifestyle details, there is slight risk of emotional discomfort and/or privacy violation. To safeguard against this, potential participants will be told clearly about the nature of these questions ahead of time, thus only those who are comfortable disclosing this information are

likely to participate. Ultimately participants will only have to reveal the information that they are comfortable revealing.

Data Collection

We will obtain permission from participants to collect data in the form of video, audio, photographs, and researchers' notes. This data will be used to create transcripts of the interviews, which can then be analyzed. Video and photographs will be used to document the objects, technologies, and locations that the participant will show us and discuss. The contents of these will also be analyzed.

All information collected will be anonymized. No identifying information will be kept alongside the data. As well, the collected information will be digitally recorded and transcribed; transcriptions 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.

Public presentations of the results will primarily present the results in an anonymized form. Where individual participant data is disclosed, such as exemplar comments via quotes, we will ensure that the selected data does not suggest participant identities.

Data will be kept for three years or until the study analysis is completed. At this point, it will be permanently destroyed.

Analysis

We will use standard qualitative analysis techniques such as descriptive statistics, and narratives to analyze participant responses. We may also compile personas depending on common traits discovered among participants. Common themes and patterns from the study will be extracted based on the observations. We will also analyze the data via various "lenses", i.e., theories and perspectives, where we will see how actual behavior matches or differs from predicted expectations. A literature review written prior to this study will be revisited to facilitate the process of matching past theories to current observations.

The possible implications of the results include:

a) A better understanding of the natural communication patterns of patients and their family members.
b) A better design of communication tools or systems for patients coping with the treatment of a chronic illness.