
Shared Displays to Facilitate Discussions Surrounding Patient Data

Haley MacLeod

University of Calgary
2500 University Drive NW
Calgary, AB T2N 1N4 Canada
hemacleo@ucalgary.ca

Anthony Tang

University of Calgary
2500 University Drive NW
Calgary, AB T2N 1N4 Canada
hemacleo@ucalgary.ca

Motivating Study

Our current interest is in supporting the self-management behaviors of individuals with chronic illness through personal informatics tools. A prerequisite for this is effective data collection, and mobile devices (such as smartphones) offer the ability for this data collection to occur in a timely, in situ manner. For example, people with chronic pain fill out “pain diaries” trying to detail each incident of pain along with intensity and possible precursors. Consequently, patients often forget about the intensity, time of onset, and duration of the pain, and they frequently forget to fill out the diary altogether [1]. In contrast, a smartphone-based application can facilitate immediate data entry (e.g. [3,4,7]). This can further be augmented with other digital sensors to collect information without explicit user intervention (e.g. [2,3,5,9]).

We are motivated by the recent popular interest in personal informatics, or the process/tools used to support collection and reflection of personal data [6]. Li and colleagues report on studies of personal informatics enthusiasts, who build sensors to collect personal data about themselves as well as visualization tools to explore and understand the resulting data [6]. These enthusiasts touch on domains such as personal finance, productivity, communication history, or mood. What

seems to set these individuals apart is that they show a genuine curiosity and interest in a self-discovery process. We call this the “personal informatics lens”: *self-motivated curiosity and interest in self-discovery*.

Our most recent work involved an interview study with individuals who employ personal informatics practices in relation to a chronic illness, in which we explored the design of tools for the management of chronic illness through this personal informatics lens. To understand these personal informatics needs and practices, we conducted an interview study, focusing on motivations for and methods of collecting data, and as well as use of the data for those with chronic illness. To help frame our understanding, we recruited personal informatics enthusiasts (without chronic illness) for a pilot study, and participants with chronic illnesses for our primary study.

Our findings as a whole suggest that self-discovery is a powerful lens for understanding the management practices of some with chronic illness. We saw that a motivating factor is the desire to take re-take control of their lives given an illness. To frame their data collection, participants articulated several different kinds of questions/concerns. There were five kinds of questions participants asked about their personal data: episodes, triggers medication, status, and history. Questions about episodes, triggers and medication are unique to participants with health concerns, while status and history questions are similar to those identified by Li et al. [22] in their work with data enthusiasts.

These kinds of questions are centered on self-discovery— understanding what the nature of particular

episodes are, what brings on the episodes, what can mitigate it and so forth. What is important here is that for some participants, it is an on- going, long-term process—perhaps owing to the changing nature some of these conditions.

Through this study, we also learned that in many cases patients share the data they collect with their providers, and we are beginning to explore possible design concepts for technologies that enable that sharing.

Designing Technology for Supporting Patient-Clinician Communication.

Smartphones provide patients with an effective way of collecting data about their health; they can enter data into apps in the phone, but also make use of the phone’s built-in sensors and other technical capabilities. Many patients see value in sharing this data with their health care providers, and in many cases the providers ask for the data. There are numerous ways in which the sharing of this data may provide value and aid patient-clinician communication. We are interested in the role of this data in facilitating discussions between patients and their health care providers, which can lead to a better understanding by patients of the nature and management of their conditions.

Data stored on the smartphone all the time, however, is difficult to share, whereas a shared display between patient and provider would allow both parties to see and discuss this data together, even if the patient is collecting data separately outside of the clinical environment. This display would allow both parties to see the same data.

An effective screen design should be large enough that either party could easily point to or refer to elements on the display. In addition, the display should provide the patient and clinician with tools for reflection, enabling them to filter through data, view a bigger picture overview, or narrow in on specific pieces of data. The analytic tools should provide visual or graphical representations of the data, drawing attention to significant data points such as potential triggers of episodes, trends and patterns, the effect of a change in medication, or changes in the condition over time.

To be solely concerned with just the technical components in the environment would be superficial. We are interested in examining the process the tool should support. Specifically, we are interested in how best to engage a patient's curiosity about their own data, and how discussions about the data may motivate them to engage in certain behaviors.

My Goals for this Workshop

I am interested in identifying emerging technologies that could support a discussion between patients and clinicians to help engage a patient's curiosity about their condition and to motivate them to implement certain changes in their behavior.

Additionally, I am interested in better understanding the possible side effects of implementing these technologies, and how they might impact clinical practices, or a patient's perception of the quality of the care they are receiving.

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