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The Challenges of Individuality to Technology Approaches to Personally Collected Health Data

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Abstract

While patients' increasing willingness to collect personal health data portends improvements in the individualization of health care, helping health care providers to effectively act upon these personal data collections poses its own challenges. In this paper, we discuss the challenges we have noticed as we work towards the creation of tools to help chronic patients present their data to their clinicians.

Author Keywords

Visualization; Personal Health Data; Technology for Communication.

ACM Classification Keywords

H.5.m [Information interfaces and presentation (e.g., HCI)]: Miscellaneous

Introduction

Tracking and collecting personal health data is becoming more common among patients [2]. These personal health data collections are typically very individual. Each patient may have different goals for collecting their data such as preventing more complications, having more control in their health outcomes, improving their management of their condition, preventing their health conditions from getting worse, as well as helping clinicians with making a more personalized diagnosis. In addition to improving patient-clinician

communication, patients can gain other benefits from collecting personal health data. For instance, having this data makes it possible for patients to review their own health situation, which can empower them in making decisions about their care. However, there are many challenges patients experience when gathering, sharing and discussing their data. Limited time, clinicians' varying expertise, and clinicians' individual modes of practice are some of many well discussed communication issues [7]. Below we also note several other issues that may arise from the process and nature of collecting personal health data.

Visualizations, which have the potential to summarize data and to clarify its presentation, may be a fruitful research direction. However, designing visualizations and other technologies for patient-clinician communication is a complex problem. This problem is receiving considerable attention (e.g. [6]) yet is far from a solved problem. In fact, it is still unclear if and what types of technologies are appropriate for supporting patient-clinician communication. In this position statement, we discuss the challenges related to the collection and utilization of personal health data that are based on our own experience of regular on-going discussions with clinicians, as well as our initial observations from interviews with patients who collect personal health data.

General Challenges

As in all good design, it is important to understand this problem from both patients' and clinicians' perspectives.

Patient interviews can reveal patients' experiences at collecting, maintaining, transferring, and discussing their health data with clinicians. However, recruiting patients who are willing to give their time and discuss their condition and their collected data is difficult. Some patients are reluctant to share information about their interactions with clinicians

since they may be concerned the information could be revealed to their clinicians. Despite informing patients about the research ethic rules of keeping the patient data private, this hesitancy can still exist. In some cases it is helpful to look at patient-generated data to get a sense of real-world examples of data. In these circumstances, it is even harder to find participants. Many patients rely on their memory to keep track of their health data, so they do not have any written record of their data to share with researchers. Also, among those patients who do collect, record, and maintain their data many use apps or tools that do not provide an easy way to export or share their data. Lastly, even if they have their data saved and accessible, many patients are not willing to share their data with researchers.

Finding clinicians willing to give interview time is also a challenge. To understand the interactions happening between clinicians and patients, we need to include clinicians who have experience with patients who do collect their own data. Clinicians who regularly see patients in their office/clinic for diagnosis or treatment purposes are usually very busy due to the nature of their practice. In addition, some clinicians are skeptical of the value of technology research. Thus, they may not be receptive to the idea of participating in research studies for designing new technologies. However, interviewing this group of clinicians may reveal many technology challenges that limit their practice.

Clinicians' Perspectives

While clinicians recognize the potential of personally collected data, the reality may be overwhelming.

Requesting: Clinicians are aware that for some conditions, they may be able to improve patients' quality of life if they had access to more details about the patient. In this situation, a clinician may ask the patient to collect data. Often,

clinicians ask for data in a particular format. Sometimes these formats are paper forms with blanks to fill in and sometimes they are digital. This is not because of a wish to control the patient. However, clinicians want data to be collected in a way that clinicians can retrieve the information they need.

Receiving: Clinicians receive both requested and unrequested data. The patients may provide unrequested data because they believe it to be relevant. However, the clinician may or may not view it as relevant. The clinician will be hard pressed to find the time to examine unrequested data in the very short time of the visit.

Utilizing: Clinicians do their best with the data they receive, but often the data has missing parts or is difficult to read. By working within the constraints of the clinical visit, the clinician may not derive as much benefit from patient-collected data as is possible.

Patients' Perspectives

From patients' perspective, it seems that every step in the data gathering process can be a challenge and these challenges might invite technological interventions.

Collecting: Currently there are already many technological ways to collect some types of health data such as: number of steps taken, variations in weight, and blood sugar levels [2]. The available technology has arisen in response to general public interest and less in response to clinicians' interests or to the individual needs of patients. Take for example a seriously chronically ill patient for whom clinicians might be able to provide better support if they had more consistent data. However, such a patient may well have pain levels that are too high to cope with current technology. One technological challenge is to design and create technology that better approaches effortlessness (e.g. [4]).

Data collected by hand suffers all the challenges of consistency in timings, in what is noted down, in frequency and in persistence.

Storing: Storing data can be an issue when data is collected by hand or by use of technology. One issue with technology collected data is that each brand of technology has their own storage methods and most only given limited access to the raw data collected. On the other side, hand collected data, may need an extra step to store it in digital format. As a result, the data is often stored on paper, in notebooks, and in journals where it can be interspersed with different types of personal information. There are many opportunities for technology to improve how it handles storing data. Technology can support integrating data collected from different sources, including digital sources and handwritten personal notes, or digitizing handwritten notes.

Accessing: Most current personal data collecting devices often only give limited access to the data collected. Although hand collected data is entirely in the patients' control, there is no limitation in the type of access they have. However, hand collected data can be less organized and thus hard to see important things such as trends, and changes. Perhaps technological intervention could make the biggest difference here. The effort has been made and the data has been collected; only the full benefit of the possible rewards has not yet been seen.

Sharing: When collecting personal health data, usually only part of the goal is to better inform themselves. Usually part of the initial goal is to share this data with their clinicians [3]. In this situation, all the troubles that plague patient-clinician communication arise again. Due to a shortage of time, the clinician may not take the time needed to glean all important information collected by the patient. Nat-

ural fluctuations in the patient's life create varying rhythms of data collection. Patients may have difficulty seeing patterns with inconsistently gathered data. Without help this sharing process can be frustrating for both the patient and clinician. This can be frustrating for the patient because it feels like their efforts are not appreciated, and frustrating for the clinician because they would like to be able to include this data in their diagnosis.

Next Steps

Since all factors (the type and number of medical conditions, the circumstances of the patient, the collection practices and accuracy) about personal health collection vary significantly from patient to patient, looking for a circumstance where this intense individuality maybe generalized is unlikely [5]. Perhaps an approach is to take advice from [1] and initially work towards good point solutions that satisfy one set of conditions. It is possible that from a set of point solutions generalities may emerge.

About Workshop Participants

Fateme Rajabiyazdi is a Computer Science PhD candidate at University of Calgary under supervision of Drs. Carpendale and Oehlberg. Her research focuses on design and development of technologies for improving patient-clinician communication. She has a close collaboration with a medical research team, Ward of 21st Century.

Charles Perin is a Lecturer in the Department of Computer Science at City, University of London and part of the giCentre. His research interests include the design and study of new interactions for information visualization, understanding how people use and interact with visualizations in their everyday lives, and human-centered design for specific applications such as sports and health.

Sheelagh Carpendale is a professor in Computer Science and Computational Media Design at University of Calgary. Her research focuses on interactive information visualization. She has on-going close collaborations with medical research teams such as Dr Ghali's Ward of 21st Century and Dr. Hill's Stroke Neurology team.

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