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

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Abstract

While patients increasing willingness to collect their personal health data portends improvements in the individualization of health care, making it possible for the health care providers to effectively act upon these personal data collections poses its own challenges. In this paper, we discuss the challenges we are facing as we work towards the creation of tools to help patients present this data to their care givers.

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 personal health data is becoming more common among patients. Among those, patients who suffer from chronic conditions are more encouraged to collect their health data. They may have different goals in mind for collecting their data such as preventing more complication, taking control and managing their condition, maintaining their health condition, and helping clinicians with the process of diagnosis.

Reviewing the personal health data empowers patients for making decision for their care either at home or when they visit clinicians. However, there are many limitations for sharing and discussing patient's data with clinicians during a medical visit. Limited time, clinician's different expertise and practice etc. may interfere with smooth communication between clinicians and patients.

Designing visualization or technologies for clinician-patient communication is a complex problem that is already receiving considerable attention (e.g. [2, 4]). It is still unclear if, when, and what types of technologies are appropriate for supporting the data communication between clinicians and patients. Designing and developing technologies for improving this communication among clinicians and patients is still far from a solved problem. Thus, in this paper we discuss the methodological opportunities and the challenges researchers may face in a) understanding clinician-patient communication challenges when discussing data; b) designing appropriate technologies to improve this process; and c) investigating clinicians' and patients' reception towards the designed technologies.

Understanding Both Parties' Perspectives

There are different methodologies to study patients' and clinicians' perspectives about collecting, maintaining, and sharing patient-generated data including observing the interactions during a medical visit and interviewing both parties.

Choosing observation as the method to gain undestanding of clinicians' and patients' interactions has its own advantages and disadvantages. One can never be sure if or when a communication challenge may occur. In clinician-patient relations, the indication is that clinicians usually only have trouble with 1 in 6 of their patients [1], and usually the communication issues with a given patient have just one challenge. Thus, collecting a broad overview of communication challenges via observation would be lengthy and likely to be incomplete.

In addition, when researchers observe the clinician-patient interactions during a visit, there may be the effect of being observed by a third person. Being observed or recorded can affect both patients and clinicians in sharing sensitive manners. However, observation method can serve us better if our aim is to analyze non-verbal cues such as facial and body gestures happening during an interaction [3].

One of the strengths of interviews is that it is possible to ask the questions in which you are directly interested instead of observing the interactions for a long time. Furthermore, interviews give both patients and clinicians the chance to share their thoughts in a timely manner.

Clinician

One way to shed lights on clinicians' perspectives about discussing patient-generated data with patients during a medical visit is to study clinicians' perspectives. It is important to interview a set of clinicians with a wide variety of expertise. Each clinician may have a different experience depending on the type of patients they visiting, their own practice, and the healthcare service they practice medicine.

However, finding clinicians willing to give interview time is a challenge. Furthermore, to understand the interactions happening between clinicians and patients, we need to include clinicians who regularly do have typical visits in their practice where they see patients in their office/clinic for diagnosis or treatment purposes. These particular clinicians are usually busier due to the nature of their practice as opposed to clinicians who are not directly interacting with patients. Therefore, recruiting clinicians who are in direct interactions with patients as participants for interviews are harder due to their time constrains.

In addition, in our experience some clinicians are skeptical of the value of technology research. Thus, they may not be very 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. Only interviewing clinicians with a positive attitude toward technology research can potentially biased for a particular solution approach.

Patient

Patient interviews can reveal patients' experiences at collecting, maintaining, transferring, and discussing their health data with clinicians. However, recruiting many patients who are willing to give their time and discuss about their conditions 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, the hesitancy from some patients still exists.

In addition, 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 the right population of participants.First, many patients still 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. Second, 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. Therefore, this is another obstacle for them to access their data bring it with them to an interview session or sending it electronically. Lastly, even if they have their data written in a notebook or saved on in a format of an app, many patients are not willing to share their data with researchers.

Designing New Technologies

The next step is to design prototypes based on the understanding gathered over the course of interviews and observation studies. The process of designing a technology prototype is an iterative process involving several phases of sketch, design, implementation, and critique with both patients and clinicians.

Running participatory design workshops to share and critique designed prototypes with both clinicians and patients is necessary. While inviting clinicians and patients to simultaneously discuss the prototypes can be enlightening, it can also be challenging. Clinicians or patients may hesitate speaking their mind with the presence of the other party. While, conducting participatory design workshops separately with clinicians and patients may be a solution to this problem, the discussion can lose some richness.

Studying Clinician and Patient Reception Towards New Technologies

Finally, designing new technologies for this domain is difficult, as clinicians are sometimes reluctant to adopt technology into their practice [5]. The structure, demands, and requirements of the healthcare system, along with how short most clinician-patient communications are, are important factors to take into consideration to improve the adoption of clinician-patient communication tools. It can be a good idea to first focus on situations where clinicians are starting to use communication technology support, since this use could indicate that clinicians can be more ready to accept technology in these settings. If they are more willing to accept technologies in these areas, it is possible that further adoption would pose fewer disruptions.

Conclusion

There are many technologies designed for collecting personal data. However, there is less focus on designing technologies that leverage sharing patient-generated data with clinicians. Designing right technology for a general population of patients and clinicians may not be possible at the beginning. Designing more solution points in this context may gradually help us shape a holistic understanding of how to design technology for supporting in-clinic communication.

To continue this path, we need to consider the reasons behind the success of these technologies. It is possible that the reason behind their success is the consideration of both clinicians' and patients' perspectives in their design. Based on our previous experiences studying clinician-patient interactions and designing new technology prototypes in this space, we have discussed the potentail opportunities and challenges we have faced. Example of challenges are recruting the right population as participants, accessing patient-data, including both parties simultanicely in study session, and skepticism on adapting new technologies.

About Workshop Participant

Fateme Rajabiyazdi is a computer science PhD candidate at University of Calgary under supervision of Prof. Sheelagh Carpendale and Prof. Lora Oehlberg. Her research focuses on design and development of technology prototypes for improving communication between clinicians and patients. She works in an interdisciplinary area between computer science and healthcare. She has a close collaboration with a medical team called Ward of 21st Century. This workshop is an opportunity for her to share her experiences working with two groups of researchers from healthcare and computer science.

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