
Data Dialog: Facilitating Collaborative Decision Making through Data-Driven Conversations

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PervasiveHealth '17, May 23–26, 2017, Barcelona, Spain
© 2017 Association for Computing Machinery.
ACM ISBN 978-1-4503-6363-1/17/05... \$15.00
<https://doi.org/10.1145/3154862.3154921>

Workshop on Leveraging Patient-Generated Data for Collaborative Decision Making in Healthcare

Abstract

Shared decision-making is a process that requires active participation from the patient in making treatment related decisions [5]. Through this process, both patients and clinicians develop a shared understanding about the patients' lifestyle choices and how they affect symptoms to make informed treatment related decisions. However, there are communication and process barriers to developing this understanding, including lack of medical knowledge on the part of the patients and lack of standard processes for clinicians to follow. With *Data Dialog*, we propose a data-driven approach to information exchange between patients and clinicians, using visualizations as 'boundary objects' for communication and collaboration. We outline a number of scenarios in which Data Dialog can be useful, and discuss opportunities and challenges that need to be addressed.

Author Keywords

participatory data analysis; visualization; collaborative decision making; data-driven conversation.

ACM Classification Keywords

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

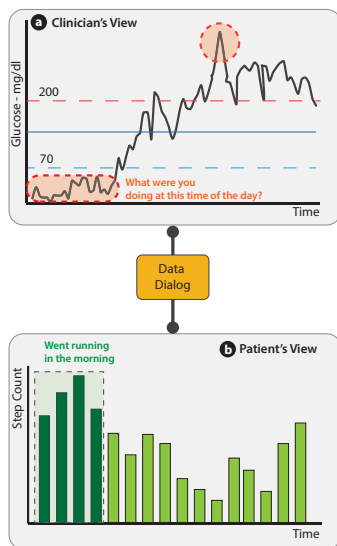


Figure 1: Collaboration between Clinician and Patient using data visualizations as boundary object. Top: Clinician selects low blood sugar readings and annotates with the question “What were you doing during this time of the day?”. Bottom: The corresponding time window is highlighted for the patient on their physical activity view, and the patient responds that they went running.

Introduction

For patients with chronic health conditions, such as diabetes and hypertension, care-management involves: (1) establishing an *ongoing* partnership (with the clinician), (2) information exchange, (3) deliberating on options, and (4) making decisions and acting on them [8]. Here, patient participation is crucial, as treatment is largely carried out by the patients themselves in clinically-uncontrolled settings (e.g., insulin injection), and treatment-related decisions have to be tailored based on individual experiences, needs, and preferences. To be effective, the clinician must understand enough about the patient’s lifestyle (diet, physical activity, etc.), and the patient must understand how medications and everyday lifestyle choices affect their symptoms. Yet this information exchange between patients and clinicians remains a challenge. Clinicians often rely on the patient’s ability to recall symptoms and behavior, which can be inaccurate and incomplete. This impacts the treatment recommendations they make. Consequently, patients are unable to understand or decide between treatment options, hindering their active participation in *shared decision-making* [5].

One potential approach is for patients to self-monitor their symptoms and other data (e.g., blood glucose levels, blood pressure, weight) and bring this “quantified-self” (QS) information into the clinical setting. The clinicians can provide context for the patient by showing how the data correlates with the clinical *health records* (e.g., lab reports, notes). However, existing work has shown that while clinicians find self-tracked patient data useful, the data is often represented in ways that may not be usable (or interpretable) by the clinicians [12]. On the other hand, patients may not understand clinical representations of data (EKG, x-rays, etc.) due to the lack of medical expertise. To solve this problem, we need a communication framework that works for individuals with different expertise, and a set of visual transforma-

tion techniques that allows for knowledge sharing across different representations of data.

In this paper, we propose *Data Dialog*, a new collaborative visual analysis approach. Data Dialog is intended to support *participatory data analysis* (PDA) [3] to enable information sharing and collaborative decision making. Through PDA, patients and care providers (clinicians, nutritionists, fitness experts, etc.) can develop a *data-driven* treatment plan—where both data, and analysis, can come from provider and patient working together.

Data Dialog

Within patient centered care, the patient engagement model consists of five stages of engagement: Consumer, Connected Patient, Contributing Patient, Conferring Patient, and Challenge-Setting Patient [1]. At the peak engagement level (challenge setting), the patient actively manages her health by setting wellness goals with advice from a care team and access to medical information. This relies on the fact that the patient is able to hypothesize about various correlations and causal mechanisms between symptoms and behavior, and to understand medical information for goal setting and monitoring progress.

In Data Dialog, we leverage PDA as a way of promoting patient engagement using data visualizations as ‘boundary objects’ [11] between patients and providers. PDA is a process in which the person whose data is being analysed (e.g., patient) is directly involved in the analysis of data [3]. It facilitates mutual-learning between participants through active engagement and collaboration. Using Data Dialog, clinicians, along with patients can model causal relations (e.g., “insulin level goes down in the morning because patient goes for a run”) and prescribe tailored plans (Figure 1). Patients can better understand how their lab test

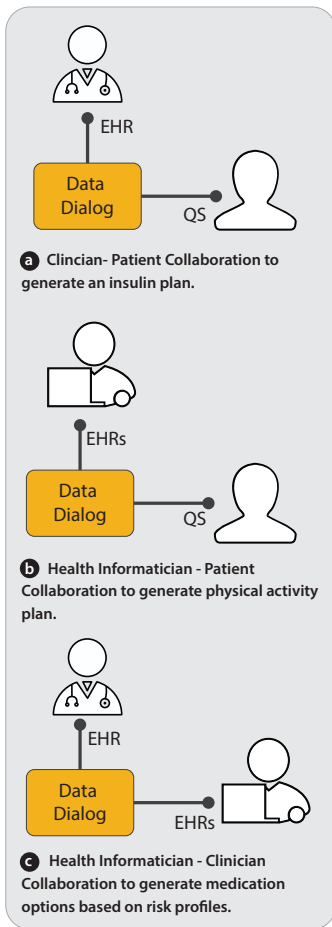


Figure 2: Collaborative analysis scenarios between patients, clinicians, and informaticians using Data Dialog.

results correlate with everyday lifestyle choices, which can increase self-efficacy and lead to improved self-care. It also provides an opportunity for patients to learn how to generate insights from data.

Roles: Patient, Clinician, and Health Informatician

PDA can be time consuming for clinicians, who may not have the time to actively engage in the process with all of their patients. O'Brien and Mattison describe the (emerging) role of data scientists and health informaticians as critical to achieving the desired state of hyper-collaboration (with patients) within healthcare [9]. We believe that the emerging role of health informaticians who have sufficient analytical and medical expertise will be able to offload analysis work from clinicians. Just as with other medical procedures (e.g., a pathologist examining a blood-draw sample) in PDA, the informatician could conduct collaborative analysis with the patient, and clinicians participate in decision making based on insights generated from data. This requires innovation around electronic health records (EHR) for reporting the outcome of PDA. In the same context, Patient Health Records (PHRs) are increasingly looked at as a way of supporting patients in managing their own health [10]. In the Data Dialog project, we plan to explore design and policy related issues around EHRs and PHRs.

Scenarios

Consider a scenario in which a patient with Type-1 diabetes and the clinician are going over the patient's insulin plan together (Figure 2a). Here, the patient has her QS data on a tablet device and the clinician has her health records on a desktop. During the analysis process, the clinician may observe and *highlight* unusual events of low-blood-sugar (on a visualization), and ask the patient if she missed taking insulin on those days. The patient remembers that she went running, but had taken her insulin shot. This insight may

prompt the clinician to revise her insulin plan, and explain that a physical activity lowers blood sugar levels.

In a different scenario, a pre-diabetic patient is working with a health informatician to generate a physical activity plan (Figure 2b). Here the informatician may first look for other patients with similar profiles, and run an analysis to identify successful recommendations for overcoming pre-diabetes. The informatician and patient engage in deciding the plan most feasible for the patient.

In a third scenario, the clinician and informatician try to determine medications for a patient that maximizes benefits and minimizes risks, based on similar patient profiles and their treatment history (Figure 2c). The informatician can present the results from data analysis performed to answer the clinician's specific question, which may trigger further questions. They can repeat the process until the clinician identifies appropriate medications.

Framework

Most collaborative visualization tools are designed for people with similar skills. But patients, clinicians, and informaticians all have very different background, (data and visualization) skills, goals, privacy requirements, and access devices (e.g., computers, tablets, phones). This calls for a new collaboration framework, and approach that supports visual analysis across different user interfaces, different levels of data abstractions, and even different visualizations.

Our research seeks to (1) model different data representation needs, (2) identify the analytical questions of patients and clinicians (those that are of mutual interest as well as those specific to each) and develop visual analysis and decision support tools, and (3) design and evaluate new collaborative technologies for participatory data analysis to generate action-oriented recommendations [4].

Discussion

With advancements in personal health trackers, there is a growing interest in leveraging QS data towards personalized medicine. By analyzing this data, Computer supported decision systems (CDSS) such as Omada [6] are providing tailored healthcare plans for individuals with pre-diabetes. Other services such as the Apple Research Kit [7] are using this data to generate insights about health behavior across different health conditions, at scale. While these approaches are useful towards making generalized recommendations, without sufficient context, it is hard to personalize the recommendations. Patients, on the other hand, may lack the motivation and expertise to do their own analysis. An unfortunate outcome is that “self-monitoring” in itself becomes the end goal and a reason for abandonment of health tracking devices. We believe that Data Dialog can alleviate this problem through PDA. For providers, Data Dialog lowers operating cost (e.g., readmission) by improving secondary care outside of the hospital. To quote Berwick et al. “. . . the actual causes of mortality in the United States lie in the behavior that the individual healthcare system addresses unreliably or not at all. . .” [2]. In summary, both patients and providers can benefit from our data driven approach to shared decision-making.

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