Personal Patient-Generated Data Visualizations for Diabetes Patients

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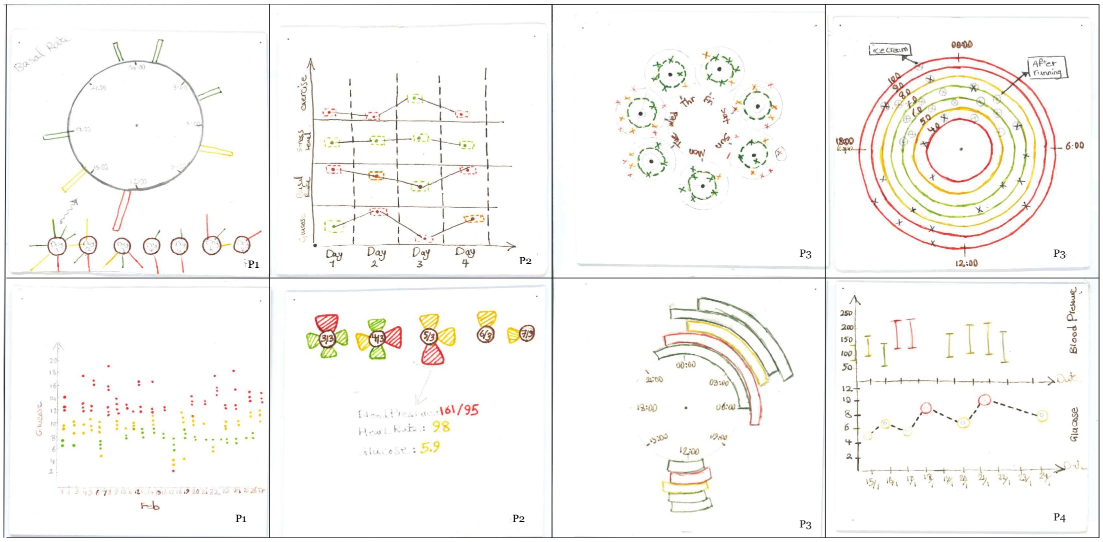

Figure 1: Personal Visualization Designs for our Patient Participants with Diabetes.

Abstract

Patients with chronic conditions are usually advised or are self-motivated to track their health data at home and present this data to the healthcare providers during clinical visits. However, often these patient-generated data collections are large, complex and individual. These characteristics make it challenging and time-consuming for providers to understand this data during short clinical visits. We interviewed four diabetes patients and obtained a sample of their data collections to understand their personal lifestyle and perspectives on the process of tracking, recording, and presenting their data. Based on the information we gathered from patients in our study, we designed various personal visualizations tailored to them.

Index Terms: Human-centered computing—Visualization— Visualization application domains— Information visualization;

1 Introduction

We designed various personal visualizations to represent diabetes patients' self-generated data collections with consideration of their lifestyle, their relationship with the providers, their conditions, and their data. Tracking and collecting personal health data is becoming more common among patients with chronic conditions [1]. These patients have a high incentive to track their health data due to the nature of their conditions that requires close self-monitoring. Each patient may have different goals and motivations for collecting their health data. These goals can range from preventing more complications, having more control over their health outcomes, improving their conditions, to sharing these self-collected data with their providers hoping to receive more tailored medical advices and to help the providers make more personalized medical decisions [2].

Healthcare providers also think they can provide the patients with more tailored care and make data-informed decisions when they have access to patient-generated data collections [2]. However, due to a shortage of time, providers may not be able to glean all the important information collected by the patients and give useful advice. Providers do their best with the data they receive, but often the data has missing parts or is difficult to read all at once. By working within the constraints of the clinical visits, the providers may not derive as much benefit from patient-generated data collections as is possible. We think visualizations, which have the potential to summarize data and to clarify its presentation, may be a promising direction to represent patient-generated data.

To visualize these data, we first needed to gain a better understanding of patients' perspectives on why and how they track, collect, and share their self-collected data with their providers during clinical visits. Thus, we interviewed four patients with diabetes and obtained a sample of their self-collected data collections. We chose to interview diabetes patients since diabetes is one of the most common chronic diseases across the world [8] and we had access to these patients through our collaborators from a local hospital.

The results of our interviews revealed how patients manage their conditions differently depending on the state of their health, their health goals, their other conditions, and their relationship with the providers. As a result, the patient-generated data collections were very different, complex, and individual. Based on this understanding, we decided to design various personal visualization alternatives for each patient representing their patient-generated data collections.

2 Patient-Generated Data

Many technological tools have become available to support people with tracking personal data such as sleep, steps taken, and weight change. With the presence of these tools, tracking and visualizing

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Table 1: Patients Demographics Information.

P#	Sex, Age	Conditions	Provider care team	Data collection motivation	Collected data item(s)
P1	M, 52	Type 1 Diabetes	Endocrinologist, nurse educator, foot care clinic	Advised by endocrinologist and nurse educator	Glucose level, basal rate
P2	M, 43	Type 2 Diabetes, hypertension, depression	Family physician, nutritionist, pharmacist, counselor, case manager	Advised by family physician	Glucose level, blood pressure, heart rate, medications, exercise
P3	F, 49	Type 1 Diabetes, meningitis, gastroparesis, diabetic retinopathy	Endocrinologist, diabetic nurse, neurologist, optometrist	Manages her conditions to avoid sever situations	Glucose level
P4	M, 56	Type 2 diabetes, hypertension	Family physician, diabetes nurse	To keep his numbers under control	Glucose level, blood pressure

personal health data is also becoming more common among patients with chronic conditions [3]. Although many tools can help people record and visualize their personal health data, most tracking technologies and health data visualizations are not designed specifically to meet patients' needs [6]. Patients have various goals, needs, lifestyles, literacy, technology skills, and attitudes towards using self-management technologies [7]. Some patients are tech savvy; they take initiative, get creative, and build their own personal data tracking and visualization tools, "Quantified Selfers" [4]. All these factors play a role in the process of tracking health data which results in very different and complex patient-generated data collections.

3 Patient Interview Study

To understand patients' perspectives, we interviewed four patients with diabetes (Table 1). We conducted an hour long semi-structured interview with each patient and asked them to bring a sample of their data to the interview session (Figure 2). We started the interviews with questions regarding the patients' health conditions, their diagnosis, their current treatment plans (if any), and their goals and personal lifestyle. Then, our participants walked us through their data sample in detail. We video-recorded, transcribed, and analyzed the interview results using open coding, a grounded theory approach. We analyzed each individual interview separately. In this poster, we present the preliminary findings of this study.

4 Patient Interview Results

Our results show how patients with similar conditions have very individual and complex data collections. Although the patients have commonalities, no two patients were the same. Thus, designing one visualization to represent these different data is not easily possible.

5 Patient-Generated Data Visualization Designs

Since all factors (the type and number of medical conditions, the circumstances of the patient, their goals and motivations, the collection practices and accuracy) about personal health collection vary significantly from patient to patient, looking for a circumstance where this intense individuality may be generalized is unlikely. Consequently, designing the right visualization to represent patient-generated data needs to be tailored for each patient. Instead of immediately pursuing a single, generalized design, we sketched variant preliminary visualization designs representing the patient-generated data collections we gathered through our patient interview (Figure 1). These design variations reflect on the patient's story.

6 Discussion and Conclusion

Healthcare systems have taken steps towards creating tailored personalized care plans for patients. The visualization literature shows that personal visualizations can better inform behavior change and support self-reflection [5]. The evidence from the visualization literature, the medical literature, and the results of our interview study drove us to think about designing personalized visualization to represent patient-generated data instead of making one visualization design that fits all patients. We encourage future researchers and designers to contribute more patient stories to the research literature and to move towards thinking about designing more for individuals.

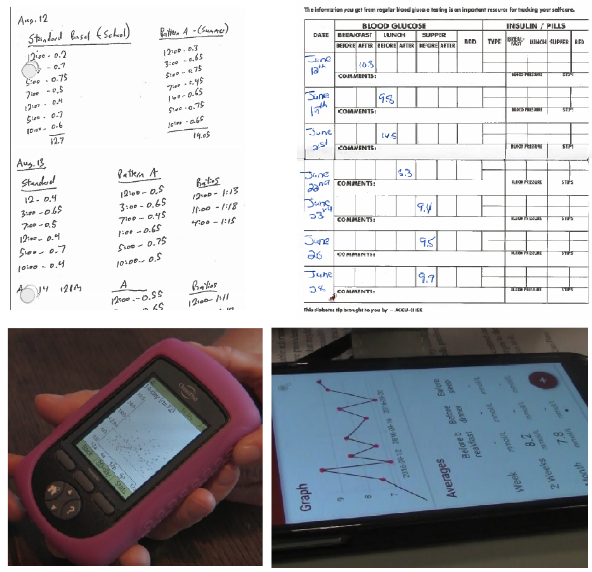

Figure 2: Top left: P1's personal notebook, Top right: P2's clinic notebook, Bottom left: P3's glucose meter, Bottom right: P4's phone.

7 Acknowledgments

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