Managing Personal Health Information in the Home: Strategies of Diabetes Patients in the US and China

Si Sun, Nicholas J. Belkin
School of Communication and Information, Rutgers University
4 Huntington Street, New Brunswick, NJ 08901
sisun@rutgers.edu, belkin@rutgers.edu

ABSTRACT
People around the world have developed many strategies to thrive with diabetes by harnessing health information about themselves and the health condition in general. This study examines the information management strategies (i.e., what people do with the information they gathered) employed by diabetes patients and how these strategies help them reach their health outcome goals. We conducted semi-structured one-on-one interviews and photo-documentation with 52 people living with type 1 or type 2 diabetes in the US and in China. These participants introduced us to a wide variety of information management strategies that take advantage of space, people and technology. Many of these strategies involve intricate data mining, information visualization, space and technology connectivity management, artwork, and other skills and techniques that are not well supported by existing tools, services and the social contexts. Our findings suggest that the personal information management activities observed in previous studies are not independent of one another. Strategies, or a personalized collection of information management activities and information items, can be just as important as their individual parts. Also, US participants reported performing different strategies at different frequencies compared to their Chinese counterparts, supporting that social contexts can influence how people manage their information. These findings can point to important directions of future developments in technology and health care services, as well as their application in various social contexts.

Keywords
Personal health information management, information management strategies, social context, diabetes.

INTRODUCTION
How people manage the information they collect can have a great impact on how effectively and efficiently they can use it. This impact can mean the difference between thriving or perishing for people living with a chronic health condition. Diabetes Mellitus (referred to as diabetes hereafter) is such a chronic illness where harnessing health information plays a crucial part in determining health outcomes. Diabetes is characterized by high levels of blood sugar caused by either insufficient insulin production by the pancreas (type 1) or by the insensitivity of body cells to insulin (type 2). If untreated, diabetes can cause complications such as blindness, kidney failure, necroses in the limbs and amputation, and even death. To reduce chances of these complications, patients need to carefully and constantly monitor health indicators such as blood sugar levels and blood pressure, their lifestyle such as diet and exercise, and other related factors such as stress. After that, patients would have to explore the relationships between the health indicators, lifestyle, other related factors, and medication usage to maintain a stable blood sugar level.

Patients may find these information-related activities confusing and overwhelming because of the large number of variables to consider, the frequency of information management activities, and the need to fine tune these activities to suit their individual needs. Nonetheless, many patients have developed personalized health information management strategies through trial and error. This study examines the personal health information management (PHIM) strategies employed by 52 people living with type 1 or type 2 diabetes in the US and China. These PHIM strategies are employed after patients collect information and before they use it. Information seeking activities can provide important settings for performing PHIM strategies and are reported when relevant.

Exploring PHIM strategies can help establish a set of patient experiences that can provide reference for both patients and health care providers and guide the design of health information technologies for the ultimate purpose of improving health care outcomes. Also, examined PHIM strategies employed by people from different social contexts can help establish a foundation for the intercultural transplant of health information technologies. Further, understanding the PHIM strategies of people living with chronic conditions can add to the literature on personal information management, offering the important perspective of a population that relies on PHIM activities for better health.

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RELATED STUDIES

Previous studies have examined PHIM from different perspectives. The work of Pratt and colleagues (2006) pointed to the importance and complexity of PHIM activities. Later, Civan and colleagues (2006) explored existing PHIM activities including information collection through monitoring and information use for health-related decision making, planning, and guiding the performance of activities. They also developed related health technology design principles with the help of seven health information consumers. This important work, however, needs more detail to fully address the diversity and complexity of PHIM activities.

From a patient-provider communication perspective, Ancker and colleagues (2015) examined issues related to PHIM including the location of PHIM responsibilities, the types of information to share with others, the information items where health information is stored, and the perception that information management is invisible to many health care providers. Focusing on patients, Whetstone (2013) investigated the information items that type 2 diabetes patients use in the home, the contexts in which these items are used, and the purpose of using these items. With an emphasis on patients’ health information use, Frost and Massagli (2008) examined patients’ experience with an online data sharing platform where they publicly share health information with others. They found that patients use health information shared by others to locate patients with certain expertise on particular questions, share their own information in anticipation of helping others, and develop and strengthen relationships with other patients living with similar conditions. Also, Almalki, Gray and Sanchez (2015) studied eleven electronic tools used by health consumers to manage quantitative health data and found that the functionality of the tools can have a great impact on people’s experiences when using these tools. These studies provide important insight into information needs, information items, information management tools, and information use, but do not offer enough detail about how PHIM activities are performed.

The literature in library and information science examined personal information management (PIM) activities in general. For example, Barreau and Nardi (1995) identified two PIM activities, including searching in an information collection and reminding of the existence of certain information. Jones (2007) proposed three PIM activities, namely finding and refinding, keeping, and meta-level activities. Using Jones’s framework, Diekema and Olsen (2014) investigated the information sources and information items used by and the sorting and storage behaviors of teachers. Also, Pikas (2008) studied how engineers organize, keep, preserve, and retrieve information. These studies focused on PHIM activities and extracted steps or processes in which these activities are performed and experienced. Differently, the study reported in this paper explore people’s PHIM strategies as a whole and emphasis the diversity of PHIM employed by different people for different purposes.

METHODS

This study adopts a mixed methods approach, including one-on-one semi-structured interviews and photo-documentation. The interviews are conducted at locations chosen by the interviewees. For participants that live more than three hours away by public transportation, the telephone or Skype is used. During the interviews, participants answered questions such as “How do you organize the information you collected?” The interviews lasted between 15 minutes and 193 minutes depending on the intensity of the PHIM activities shared by participants. All interviews were audio recorded.

Before the interviews, participants were also provided the option to participate in photo-documentation. This method uses pictures and photographs to document participants’ PHIM activities. All participants consented to both interviews and photo-documentation. Because some interviews were done at participants’ home and work place, some of the photographs were taken by the first author. When the photos were collected by participants, they were sent through emails, multimedia messages, or data-sharing services such as Dropbox. The first author prepared a list of the desired photographs during the interviews and asked for clarifications of these photos when necessary.

Participants were recruited in two countries, the US and China. All participants were recruited through snowball sampling, where the first author recruited several participants from her social network, and asked the existing participants to refer other patients who may be interested in participating. Among a total of 52 participants, 22 were from the US and 30 from China; 20 have type 1 diabetes and 32 have type 2; 30 were female and 22 were male, including 2 female participants from the LGBTQ community. All participants are over 18 years old, with the majority between 45 and 64 years old. Most of the participants have lived with diabetes for more than 3 years. In addition, a broad range of occupations were reported by participants, such as professor, student, doctor, lawyer, military veteran, writer, engineer, actor, designer, and accountant. To preserve participants’ privacy, all participants were assigned a code (e.g., P1) at the beginning of the interview.

Before analyzing the data collected for this study, the audio recorded interviews were transcribed with the photos inserted into corresponding locations in the transcript. The interviews conducted in China were transcribed in Chinese and the direct quotes used in reports were translated into English. The first author coded the transcripts with latent content analysis, which examines the underlying meaning of texts (Graneheim & Lundman, 2004). The first author discussed the codes with the second author and improved them during the process. This abstract reports results from the first round of coding. We plan to carry out three rounds of coding in total with a second coder helping with 10% of the data.
PRELIMINARY RESULTS
Participants reported a wide variety of PHIM strategies that have produced positive results for them. These strategies include: extensive recording and integration strategy, collaborated improvement strategy, location-based redundancy strategy, location-based integration strategy, creative engagement strategy, and leadership engagement strategy. These strategies are not mutually exclusive — participants may adopt a combination of these strategies to address their specific PHIM needs. The rest of this section provides a brief overview of the 6 strategies introduced above.

Extensive Recording and Integration Strategy
Many participants reported recording their health indicators and daily activities. For example, P32 keeps a scrap of paper in his wallet to record information such as his blood sugar levels, insulin injection volumes, date and time of blood sugar testing and insulin injection, location of blood sugar level testing, and diet. He updates the information on this piece of paper whenever a new activity is performed. At the end of the day, the participant transcribes the information from the piece of paper in his wallet to a row in the chart shown in Figure 1. He color codes blood sugar levels according to how high they are and calculates his daily average blood sugar levels and daily total number of blood sugar level tests. At the end of each week, he integrates data from the chart demonstrated in Figure 1 and creates a new one focusing on blood sugar levels. On this new chart, he arranges the initial blood sugar levels from low to high and summarizes the amount of insulin he used to reach certain target blood sugar levels for each initial level. He also transcribes the cell on the lower right corner of the chart (Figure 1), which shows his weekly average blood sugar levels and weekly total numbers of blood sugar tests, onto a yearly work sheet where he calculates his yearly averages.

Other participants have also used Excel spreadsheets to make graphs that show history and trends and build time series models, made use of notebooks distributed at pharmacies for recording, adopted software that come with the continuous glucose monitors (i.e., a device that monitors and charts blood sugar levels about every 15 minutes), harnessed smart phone applications that records certain health indicators and provide guidelines based on them, and wrote and reviewed free text health diaries. Participants in China did not report using technologies but many employed paper-based extensive recording and integration strategy.

Collaborated Improvement Strategy
Involving one’s social network in her diabetes information management process has been reported by some participants as particularly helpful. P38, for example, mentioned that she shares her daily schedules and location with her spouse so that if she stays at a certain location for longer than expected without notifying her family, actions can be taken immediately to counter emergencies such as life-threatening hypoglycemia (i.e., low blood sugars).

P43 takes her spouse to support group meetings so they can jointly manage her health information and add to her information collection. Her diabetes-related information is carefully labeled and shared through synchronized mobile phones and computers with her family. This joint ownership of health information seems to be more commonly observed with participants in China, many have family members and caregivers by their side throughout the interview to help answer some of the questions.

Location-Based Redundancy Strategy
Some participants found the utilization of space an effective way for information management. They keep multiple copies of their information management tools (e.g., meters and notepads) through the household and prepare additional copies for special occasions such as traveling. Participants who reported employing this strategy mentioned that they collect information for immediate use and tend to not consciously record health information. Interestingly, many of them also use a continuous glucose monitor and/or an insulin pump, which automatically records some data and require patients to input information (e.g., carb counts) in order to correctly function. Participants who use only location-based redundancy strategy without the support of
those additional tools reported that it is hard to maintain coherent records over time and share them with health care providers. This strategy is most employed by participants from the US; participants from China reported a shortage of tools to maintain redundancy.

**Location-Based Integration Strategy**

In contrast to the location-based redundancy strategy, this strategy is where patients integrate all diabetes-related information items (e.g., meters, notepads, brochures, and medical reports) in one location. Figure 2 is an example of this strategy. Participants adopting this strategy reported having limited but frequently used information about diabetes. This strategy is reported more frequently by participants from China.

There are also other location-based strategies, such as location-based reminder strategy, where participants place information items at locations of significance or are relevant to certain activities in order to remind themselves of the existence of such information.

**Creative Engagement Strategy**

A few participants use colorful drawings to record their daily experiences with diabetes and establish understandings of their health conditions through constantly going back to read previous picture diaries. This strategy is very powerful for some participants because they were highly motivated and engaged when flipping through their art work.

Some other examples of creative engagement personal information management strategies include making photo food diaries using a smart phone, designing medical bracelets holding customized information, and giving medical devices and tools a name and becoming emotionally attached to them. The creative engagement strategy is only observed among participants in the US.

**Leadership Engagement Strategy**

Participating in diabetes-related organizations and initiatives makes many participants become information gate keepers. They have more access to and become more motivated to engaging in information on cutting edge developments in diabetes treatments and newly emerged social issues. For example, several diabetes patients in (both type 1 and type 2, both from the US and from China) have established their own patient support groups. In particular, one participant is an activist in promoting education and employment equality for diabetes patients in China. He tested different theories and methods on himself and researched extensively regarding diabetes health indicators and work performance. Many leaders reported that they feel responsible for the health of people in their groups and they perceive more values in their PHIM activities when these activities can also benefit others.

**REFERENCES**


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