Personal Health Information Management in Chronic Illnesses

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Abstract
Understanding patients' personal health information management (PHIM) can help us design better information technologies for health care. This study examines type 1 and type 2 diabetes patients' PHIM, including motivators, activities, information items, and affective processes. A mixed methods approach including interviews and photo-documentation was carried out with 60 diabetes patients in the US and in China. Data analysis for 36 participants revealed 19 major categories of PHIM processes and 81 subcategories. Many of these categories are not examined in detail by existing studies. Further analysis explores the relationships between these categories and proposes design principles for health information technologies aimed to help people living with chronic illnesses.
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1 Introduction

This study explores the personal health information management (PHIM) processes of people living with chronic conditions. These PHIM processes focus on how people deal with the health information they collect on a daily basis in order to use it to help with their health goals.

With the responsibilities of chronic illness health care gradually shifting to patients and the home environment, understanding these processes becomes increasingly important. This is because harnessing one's personal health information can facilitate patients' understanding of their health conditions and assessment of available options so they can make informed health decisions. However, patients' efforts can be hampered by issues such as information overload and information fragmentation. Exploring patients' existing PHIM processes can help us understand what is working in real life settings despite the various hurdles, and what is not working, too.

This study examines four different PHIM processes, including (a) the motivations for people to carry out PHIM activities, (b) the information collection, organization, retrieval and use activities they perform, (c) the information items they use to support these activities, and (d) the affect (i.e., emotions) they experience while engaging in these activities. These four aspects are identified from theories and models in personal health information management (e.g., Civan, Skeels, Stolyar, & Pratt, 2006), personal information management (e.g., Jones, 2007), personal knowledge management (e.g., Frand & Hixson, 1998), and personal informatics (e.g., Li, Dey, Forlizzi, Höök, & Medynskiy, 2011). Based on an understanding of PHIM processes, the study aims to propose a list of design principles for information technologies that can support chronic illness management in the home. The insights into PHIM processes reported by people living with chronic conditions can also add to the literature on the personal information management processes experienced by the general population.

2 Related studies

The literature on people's personal information management (PIM) processes and information behaviors in general supports that examining the four PHIM processes explored in this study is meaningful and necessary. The motivating factors for people to perform information behaviors are observed in previous studies on information seeking activities. For example, Taylor's (1967) concept of visceral information needs, Belkin et al.'s (1982) anomalous state of knowledge, and Dervin's (1983) sense-making model all point to the tendency that the existence of a real-life problem can motivate people to look for information. Also, Wilson's (1997) model of information seeking behavior and Johnson et al.'s (1995) Comprehensive Model of Information Seeking investigated the contextual and personal factors that may motivate information seeking behaviors.

Studies have also identified a variety of PIM activities. For example, Barreau and Nardi (1995), Jones (2007), Pikas (2008) and Oh (2013) identified different collection, organization, retrieval, and use activities. A few recent studies on PIM focused on information items. Finneran (2009), for example, examined information items in connection to tasks. Oh and Belkin (2014) looked at the characteristics of

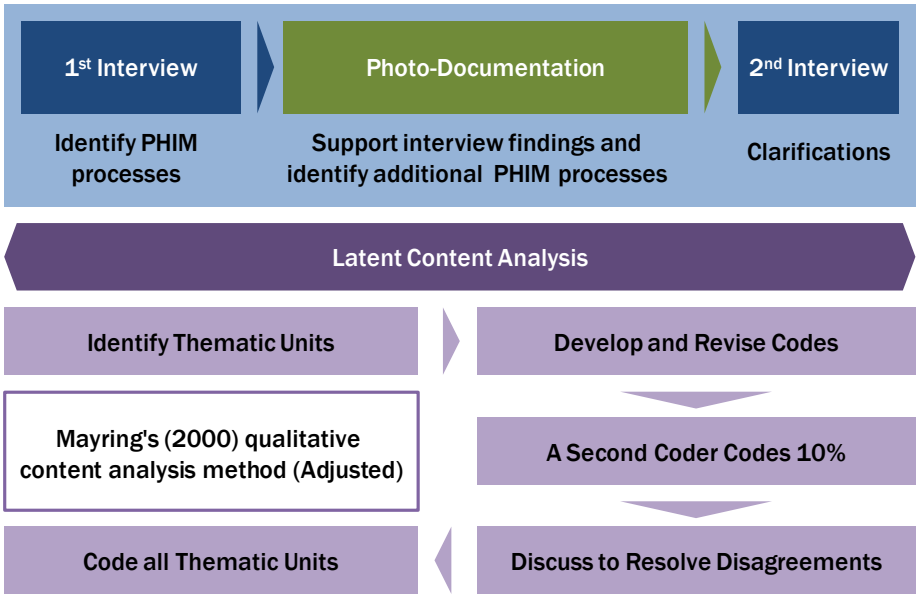

Figure 1. Research Methods

information items and how they are categorized. In addition, some information behaviors are found to be accompanied with affects. For instance, Kuhlthau's (1993) information search process model suggests that the different stages of information seeking behavior can have various affective symptoms.

The literature in PIM and other information behaviors supports that when people interact with information, they may experience the four PHIM processes central to this study. However, because many of the studies do not directly address PIM behaviors, it is unclear whether some findings, such as those on information seeking behaviors are transferrable to PIM or PHIM. Adapting PIM models and theories in the health domain can add to the complexity, as many PHIM processes can be less applicable to the general population. For example, the severity of illnesses may affect the motivations for patients to perform PHIM activities (Sun & Belkin, 2015). Therefore, it is necessary to examine PHIM processes to further our understanding of PIM.

Studies focusing on PHIM have also investigated the four aforementioned PHIM process, but require more efforts to draw a comprehensive picture. For example, Pratt et al. (2006), Civan et al. (2006), and Ancker et al. (2015) pointed to the importance of this field and mainly explored information collection and use activities. Other studies examined the information items (e.g., Whetstone, 2013), the volume of PHIM activities in relation to clinical information technologies (e.g., Nambisan, 2015), and the information technologies designed to support PHIM processes (e.g., Almalki, Gray, & Sanchez, 2015; Lucero et al., 2012; Piras & Zanutto, 2011). However, more research is necessary to establish a comprehensive model for PHIM and inquire the relationships between the diverse PHIM processes.

This study is an effort to address these gaps in the literature by observing patients' existing PHIM processes, modeling these PHIM processes and their relationships, and then applying our findings to support the design of health information technologies.

3 Methods

Figure 1 shows how our research methods are carried out. A mixed methods approach including two rounds of semi-structured one-on-one interviews and photo-documentation (i.e., taking photos of PHIM activities and information items) was adopted. The purpose of the interviews is to collect rich textual data and that of the photo-documentation is to support the interview data and identify themes not reported in the interviews (e.g., participants may not consider notes jotted down on their paper calendar as a PHIM activity and not mention it during the interview, but the notes will show up in the photos). Our research methods are supported by the Rutgers University Institutional Review Boards. All participants have granted us paper consent at the start of the interview and verbal consent for every picture taken.

A total of 60 type 1 or type 2 diabetes patients were recruited for the study. Thirty participants were recruited for a pilot study in China, where the research instruments were tested and adjusted. The other 30 participants were recruited in the US and used the improved research instruments. Comparisons between participants from two very different social background can lay the foundation for transplanting information services as a potential future result of our study.

Level 1 PHIM Processes	Level 2 PHIM Processes	Level 3 PHIM Processes
1. Motivators	1.1 Information Attributes Motivators	e.g., information availability, abundance, credibility, accuracy, consistency, timeliness, presentation style, etc.
	1.2 Medical Motivators	e.g., symptom notability and consistency, condition severity, anticipated health outcomes, etc.
	1.3 Behavioral Motivators	e.g., continuity of existing behaviors, ease of information management processes, etc.
	1.4 Social Motivators	e.g., social identity, reactions from others, exemplars, social relations, etc.
	1.5 Personal Motivators	e.g., outlook on life, interest in the activities, location of responsibility, abundance of time, trust in memory, etc.
	1.6 Financial Motivators	(No subcategories)
	1.7 Environmental Motivators	(No subcategories)
2. Activities	2.1 Collection	e.g., consulting, updating, serendipity encounter in external information collection, searching and browsing external information sources, etc.
	2.2 Organization	e.g., remembering, categorizing, marking, reproducing, formatting, connecting, etc.
	2.3 Retrieval	e.g., search, browse and serendipity encounter in personal information collection, spontaneous and reminded recall, etc.
	2.4 Use	e.g., sharing, evaluating, problem solving, decision making, etc.
3. Information Items	3.1 Paper Printable Items	clinical, personal, and public paper printable items
	3.2 Online Printable Items	clinical, personal, and public online printable items
	3.3 Digital Local Printable Items	clinical, personal, and public digital local printable items
	3.4 Audio Recordings	clinical, personal, and public audio recordings
	3.5 Videos	clinical, personal, and public videos
4. Affective Processes	4.1 Information Content Elicited Affect	information content elicited positive, negative, or neutral affect
	4.2 PHIM Activities Elicited Affect	PHIM activities elicited affect positive, negative, or neutral affect
	4.3 PHIM Tools Elicited Affect	PHIM tools elicited affect positive, negative, or neutral affect

Table 1. Preliminary Results on the Categories of PHIM Processes

Diabetes is selected for this study because it is a complex chronic health condition that requires extensive daily PHIM activities to achieve better health care outcomes. If diabetes is managed effectively, patients can avoid many health consequences, such as blindness, kidney disease, and necroses in the limbs. Both type 1 and type 2 diabetes are included because these two related conditions have many

differences and can help us explore if various health conditions would be related to different PHIM processes.

The data collected from the interviews were transcribed and analyzed using an adjusted version of Mayring's (2000) qualitative content analysis method. We have completed data analysis with all 30 participants in China and 6 participants in the US. During the analysis process, we continued to identify new themes. An overview of the findings is offered in Table 1.

4 Preliminary Results

Patients reported a wide range of PHIM motivators, activities, information items, and affect. A summary of the categories identified are presented in Table 1. Because of the limited space for this paper, most level 3 PHIM processes listed in the third column of Table 1 are examples.

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