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A sociotechnical systems approach toward tailored design for personal health information management

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Research

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Abstract
We used a sociotechnical systems approach—which conceptualizes a system of interacting people, technologies, and tasks, to identify individual differences in personal health information management (PHIM) that can inform the design of patient-friendly environments, tools, and technologies. We conducted a secondary thematic analysis of data collected as part of a parent project, vizHOME. The goal of vizHOME was to improve health and health outcomes through identifying key features in the environment that will inform the design of consumer health information technology HIT. We analyzed interview data collected from 20 individuals with diabetes. We found seven dimensions of PHIM: (1) level of privacy preferred for PHIM; (2) amount of engagement in PHIM; (3) extent of guidance preferred for PHIM; (4) level of documentation preferred for PHIM; (5) degree of physical distribution of PHIM; (6) amount of flexibility in PHIM routine; and (7) use of external cues to manage PHIM. Our results suggest that each dimension exists as a continuum, which are anchored from low to high. Exploring the interaction between PHIM and the sociotechnical system in which PHIM is performed revealed key dimensions of PHIM as well as individual differences in those PHIM dimensions. Identification of individual differences in PHIM can support the creation of human-centered design considerations for tailored environments, products, processes, and technologies that support PHIM. Future research will seek to validate PHIM dimensions in a larger population and develop a PHIM-typing measure to identify PHIM types toward tailoring processes, products, and to individual needs in context.

Keywords
Personal Health Information Management, sociotechnical systems, Human Factors/Ergonomics, Diabetes, human-centered design

Introduction

Chronic illness management has shifted the burden of healthcare from clinicians to patients, and the location of healthcare from the hospital to the home.[1] These shifts, combined with rising prevalence and potential of patient-facing consumer health information technologies (HIT) such as patient portals, e-visits, internet-connected self-monitoring devices, and mobile health apps has led to increased reliance on patients managing their health information at home.[2,3]

However, personal health information management (PHIM) is a persistent challenge for patients and their families. This has been attributed to a multitude of issues such as the fragmented healthcare system, misperceptions about who is responsible for managing PHIM, the overwhelming amount of information patients are required to manage, and the wide variation of types and forms of information such as appointment scheduling, symptom monitoring, and medication schedules.[4,5]

Consumer HIT, defined as "computer-based systems...designed to facilitate information access and exchange, enhance decision making, provide social and emotional support, and help behavior changes that promote health and well-being," has great promise for supporting patients with PHIM.[3] For example, patient portals can improve patient engagement with their care team and their care and eHealth applications can provide nudges to change behavior.[6] However, it has demonstrated mixed results in terms of consumer acceptance, widespread adoption, and sustainable use.[2,3] For example, consumer HIT abandonment can occur when consumer

HIT use is perceived to interfere with existing needs, impede self-management effectiveness, or lead to frustration.[7-9] To prevent consumer HIT abandonment and increase its acceptance and success, researchers have called for human-centered designed technologies that fit individuals' needs and the flexibility to interact with the context of how PHIM occurs in the home.[7,10-14]

PHIM is the set of processes and strategies people use to actively meet their health goals through finding, organizing, and sharing their health information [15-17] and has been defined as information acquisition/integration, maintenance/use, and communication.[18] PHIM includes activities such as navigating health-related websites, tracking symptoms, triggers to perform self-care (e.g., a dog as a trigger to take a walk), monitoring health states, determining when or how to take medications, and making sense of discharge summaries.[15,16]

PHIM is mainly performed in private homes, which can be conceptualized as complex sociotechnical systems—a system comprised of people, technologies, and tasks that interact with the environment (both physical and organizational) to perform processes that, in the case at hand, are likely to shape PHIM.[11,12,14,19-21] For example, recent research suggests that PHIM is performed outside of the head, and patients use the features of the home sociotechnical system to manage their health information.[14] Further, research that examined interactions between health information storage (a subset of PHIM) and the home found that household spaces support different strategies for storing health information.[22] Room layout or visual cues also can influence the ability to locate critical information or to remember an appointment.[23]

These findings provide insights into current PHIM strategies of patients, which can feed the development process of patient-centered designed products and services. Moreover, these findings also suggest that there are individual differences in PHIM strategies. Insights into these individual differences can be used as starting points for the development of tailored, patient-centered products and services for PHIM that account for the individual performing PHIM in the home in which it will be used.[3,14,24] Patient-centered designed consumer HIT can facilitate a tailored PHIM process, which is expected to lead to a more patient-centered experience associated with higher patient empowerment and satisfaction, improved health-related outcomes, as well as more efficient use of healthcare services,[25-28] However, research to date has focused largely on specific tasks of PHIM, such as individual PHIM roles and perceptions, PHIM task burden,[17] and the relationship between familiarity with technology and motivations for using PHIM tools.[29,30] A greater emphasis on research examining the individual differences in interactions between PHIM and the specific context in which PHIM is performed is needed so that these interactions can be leveraged to inform patient-centered, tailored design of environments, products, processes, and consumer HIT.

Objectives

We applied a sociotechnical systems approach to examine the interactions between PHIM tasks performed by individuals and the sociotechnical system in which they are performed. Our specific objective was to identify individual differences in PHIM dimensions that can be used to provide design insights for tailoring the design of PHIM processes, products, and tools to support individual PHIM needs.

We focused on people living with diabetes, a population burdened with many simultaneous and reoccurring PHIM demands. An estimated 442 million people globally are living with diabetes, with that number expected to rise.[31] Examples of PHIM required of people with diabetes include monitoring blood glucose, managing ingestible and/or injectable medications, scheduling appointments with clinicians, and recalling/understanding instructions from clinicians.[32]

Methods

Parent study

We conducted a secondary analysis of data collected in a parent study, vizHOME (AHRQ R01HS022548).[33,34] The goal of vizHOME was to improve health and health outcomes through identifying key features in the environment that will inform the design of consumer health information technology HIT. To accomplish this goal, our research team used a 3D scanner to create virtual replica of 20 homes, which we then used to study PHIM in the home. A full description of the vizHOME project as well as viewable and downloadable virtual replica of the 20 homes can be found at http://pages.discovery.wisc.edu/vizhome/. The University of Wisconsin-Madison Institutional Review Board approved this study.

Setting and participants

Participants were a convenience sample of 20 community-dwelling adults (65% Caucasian, 70% female, 25% lived alone) with an average age of 59 (SD=12, range=37-74).[34] All reported being told they had diabetes.[34]

Participants were from urban, suburban, and rural regions of a Midwestern state and lived in one of four home types: detached (35%), semi-detached (20%), multiunit (25%), and mobile (20%).[34] All participants had a cell phone and/or land line; all but one household had a laptop or computer.[34]

Procedure
As part of the parent study, interviews were conducted over a series of three home visits (2-3 hours each).[34] Using a contextual inquiry approach, interviews focused on three categories of PHIM: (1) self-monitoring, (2) medication management, and (3) information management.[35] Participants were asked to demonstrate how they performed self-monitoring, medication management, and information management in a typical day. While demonstrating their PHIM, participants also responded to semi-structured interview probes about their health concerns, self-monitoring tasks, and self-management practices. Interviews were completed by two researchers (interviewer and note-taker) and were audio-recorded for quality assurance.[34] A schematic map of the home was created to highlight layout and focal areas of PHIM, and task analysis grids were created to categorize a task analysis of the demonstrated PHIM tasks within a sociotechnical system structure. Grid categories were based on the elements of the Systems Engineering Initiative for Patient Safety (SEIPS) model, which represents the sociotechnical system as a structured work system of interacting elements (people, tools/technology, tasks, organization, physical environment) that produce processes and outcomes.[36] Grids were created by mapping specific PHIM tasks described by the interviewee to the corresponding SEIPS model system element or elements. Casper and colleagues provide a detailed description of parent study procedures including the interviews and the task analysis grids.[34]

Design
We conducted a secondary thematic analysis using NVivo 11 (QSR International) of the 20 contextual interviews using the three data sources: (1) task analysis grids, (2) note taker descriptions of PHIM, and (3) home maps.

Analysis
Coding was guided by distributed cognition theory, a sociotechnical theory of cognition that highlights the importance of system-level aspects of cognition,[37-39] which allowed us to identify how the cognitive aspects of PHIM interacted with different components of the sociotechnical system.[37-39] One member of the research team (AB) performed structural coding to select passages related to PHIM.[40]

Analyses of the coded passages and the initial list of themes were discussed within the multidisciplinary research team (AB, NW, PFB, GC, CAS, KP) comprised of the following fields: Computer Science, Engineering, Informatics, Nursing, and Psychology. Analysis resulted in identification of seven overarching themes that represented PHIM dimensions. Themes and passages were discussed by the research team until consensus was reached on theme names and definitions and were presented to original interviewers to ensure they accurately captured the experiences described by participants. Theme names and definitions were then transcribed into a codebook.

Next, a researcher (MT) used the codebook to code all documents. Two members of the research team (AB, MT) met regularly and discussed the identified PHIM dimensions to ensure consensus of each code. A senior member of the research team (NW) met with the coders weekly to review codes and consensus decisions. Coding further revealed that PHIM actions tended toward polarity within each dimension. For example, for the dimension "privacy," PHIM actions could fall anywhere on a continuum from requiring no privacy to requiring complete privacy to perform PHIM. To identify wzsw23hich pole of each PHIM dimension a participant fell on, the two coders (AB, MT) coded all documents based on whether an identified PHIM action was toward one end of a continuum or another (i.e., high or low). As the dimensions represent a continuum from high to low, an individual's PHIM actions could include PHIM actions that were both high and low on a particular dimension.

Results

We found that individuals' cognitive work interacted within their homes in unique ways to support PHIM. These individual differences were classified into seven distinct PHIM dimensions: (1) level of privacy preferred for PHIM; (2) amount of engagement in PHIM; (3) extent of guidance preferred for PHIM; (4) level of documentation preferred for PHIM; (5) degree of physical distribution of PHIM tasks; (6) amount of flexibility in PHIM routine; and (7) use of external cues to manage PHIM. Our results suggest that each of the dimensions exists as a continuum. Each dimension represents a range of possible expressions of that dimension, which are anchored by extremes at both the high and low end expressions.

Table 1 categorizes the PHIM dimensions identified, describes the continuum anchors for the extremes of those PHIM dimensions and their definitions, and provides illustrative examples from the data that highlight each PHIM dimension anchor.

PHIM dimension 1: Privacy
We defined privacy as the need to complete a PHIM activity without being observed or disturbed. High-on-privacy individuals wanted PHIM-related items inaccessible to others. These individuals kept health-related items in sparsely-accessed areas, such as closets and cabinets. High-on-privacy individuals often kept PHIM-related materials with them, such as within a purse or pocket. One individual kept a glucometer in the car and reported that she tries not to use it in front of others [M03 40s/Female].

Table 1. Categorization of PHIM dimensions and continuum anchors with definitions and representative examples from the data

PHIM Dimension	Dimension Anchors with Definitions	Selected Examples from the Data
Privacy *Level of privacy preferred for PHIM*	High on Privacy - People who complete PHIM without being observed or disturbed	Keeps glucometer in car and uses it there; prefers not to use around other people [M03 40s /Female]
	Low on Privacy - People who complete PHIM in shared or public spaces	Keeps pills on the kitchen counter [D01 70s /Female]
Personal Engagement *Amount of personal engagement preferred for PHIM*	High on Personal Engagement - People who actively manage PHIM	Checks bottles and pharmacy inserts against medication list in the health care provider's summary [SD01 70s /Male]
	Low on Personal Engagement - People who passively manage PHIM	Aware of glucometer's history function, but does not to use it to track blood sugar readings [M04 60s /Female]
Guidance *Extent of guidance preferred for PHIM*	High on Guidance - People who prefer advice or direction when managing PHIM	Calls healthcare provider for confirmation before discontinuing a medication they think might be causing a reaction [A01 60s /Female]
	Low on Guidance - People who rely on themselves when managing PHIM	Learned to use insulin pump using trial and error and the manual D06 40s /Female
Documentation Reliance *Level of documentation preferred for PHIM*	High on Documentation Reliance - People who prefer physical records or reminders to complete PHIM	Attaches note to calendar that specifies information for next visit to his physician [SD01 70s /Male]
	Low on Documentation Reliance - People who rely on memory to guide PHIM tasks	Uses memory to administer sliding scale insulin [D05 30s /Male]
Physical Distribution of PHIM *Degree of physical distribution of PHIM tasks*	High on Physical Distribution of PHIM People who spread PHIM tasks	Stores thyroid medication in bedroom because taken upon waking, but stores glucometer in kitchen because readings are taken before breakfast [M01 40s /Female]
	Low on Physical Distribution of PHIM People who group PHIM tasks	Stores all medications and diabetes supplies in the kitchen [SD02 60s /Male]
Routine Adherence *Amount of flexibility in PHIM routine*	High on Routine Adherence - People who strictly follow a regular schedule of PHIM tasks	Takes arthritis injections every week after Friday morning shower [A01 60s /Female]
	Low on Routine Adherence - People who easily adjust scheduling of PHIM tasks	Knows diabetes medications are to be taken two times per day, but takes medications all at once in the morning [A02 70s /Female]
External Cues *Level of external cues used to manage PHIM*	High on External Cue Use - People who use sensory stimuli as triggers or reminders for PHIM tasks	Morning news show acts as a trigger to take 8 am medications [A02 70s /Female]
	Low on External Cue Use - People who use bodily stimuli as triggers or reminders for PHIM tasks	Just takes pills when getting ready for day the day (anywhere from7am-10am) [D07 60s /Male]

PHIM=Personal health information management; Demographics presented as: Participant number/age range/gender materials. These individuals left items in plain sight on counters, tables, and dressers. Low-on-privacy individuals often used spaces in the home meant for common household practices such as eating, cleaning, or watching television. For example, one individual left her medications on the kitchen counter where she ate meals [D01 70s/Female].

PHIM dimension 2: Engagement

We defined engagement as participation and personal involvement in PHIM tasks. High-on-engagement individuals managed PHIM by actively seeking out health information, tracking/monitoring health, and using multiple sources of information to perform PHIM. High-on-engagement individuals described writing down questions to prepare for healthcare provider appointments, keeping logs of health information (e.g., blood glucose levels), and accessing patient portals to review information. For example, one high-on-engagement participant described using the glucometer's history feature to record past readings [D02 50s/Female].

We characterized low-on-engagement individuals as being passively engaged in PHIM. Low-on-engagement individuals tended not to independently seek out health information or track and monitor their health status. Instead, low-on-engagement individuals often delegated PHIM to formal or informal caregivers, clinicians, and pharmacists.

PHIM dimension 3: Guidance

Guidance was defined as reliance on advice or direction from outside influences for PHIM. High-on-guidance individuals described seeking help as a key function of PHIM, which included resources such as healthcare providers, family members, books, television shows, and websites. High-on-guidance individuals asked questions during healthcare appointments and contacted healthcare providers with questions. One participant described reading health magazines and watching health-focused television shows (e.g., Dr. Oz) to support PHIM [SD03 70s/Female]. High-on-guidance individuals also often asked friends and family members to help perform PHIM tasks.

Low-on-guidance individuals relied on personal experience as guidance for managing PHIM. These individuals reflected on the success or failure of past strategies and then used those outcomes to inform current PHIM. One participant explained that after a blood sugar reading above 300, she responded by drinking water and relaxing on the couch, instead of following the clinician's recommendation to visit the emergency room [D02 50s/Female]. Another participant described adjusting his insulin dose based on blood sugar level and what he planned to eat. He knew how much to change it from "trial and error" [D03 30s/Male].

PHIM dimension 4: Reliance on documentation

We defined reliance on documentation as the need for physical artifacts to support PHIM. High-on-documentation reliance individuals kept physical records of health information, such as visit summaries from provider appointments, prescription inserts from the pharmacy, and medication lists. For example, one participant kept a self-developed notecard with a list of current medications and dosages [D04 60s/Female]. In addition, high-on-documentation reliance individuals took notes with questions or observations for future healthcare appointments, and used planners, calendars, and white boards to manage health schedules and PHIM tasks. One participant described how he used a yellow legal pad to record his glucose readings including multiple points of information such as the time of day and whether it was before/after eating [D07 60s/Male].

Low-on-documentation reliance individuals kept minimal physical records related to PHIM. One participant explained that she did not document blood sugar, condition changes, or questions for her provider, but relied on her memory to relay her pertinent health information every three months [D01 70s/Female]. Low-on-documentation reliance individuals also described discarding physical copies of medication lists, visit summaries, and medication inserts provided by the pharmacy. Instead, these individuals also relied on memory and knowledge accumulated from past health-related experiences for instructions, doses, routines, or questions related to PHIM.

PHIM dimension 5: Physical distribution of PHIM

We defined physical distribution of PHIM as the degree of dispersion of items and activities related to PHIM within the home environment. High-on-physical distribution individuals spread PHIM across different locations of the home, and elsewhere such as cars. High-on-physical distribution individuals described using the time of day or concurrent life activities to disperse PHIM throughout the home. For example, one participant explained that she stored medication on the bedside table since she took that medication upon waking and stored a glucometer on the kitchen counter since she took blood sugar readings before breakfast [M01 40s/Female].

Low-on-physical distribution of PHIM individuals grouped health-related information in a central location in the home. We found that these participants tended to focus on kitchens, bathrooms, or bedrooms for grouping PHIM. For example, one participant stored all medications in a bin and returned to the bin throughout the day when it was time to take medications [A03 40s/Female]. Another participant described the kitchen as the central PHIM location, storing her medications in cabinets, checking blood sugar at the kitchen table, as well as conducting internet searches about health conditions/medications and communicating with providers through a patient portal at her kitchen counter [D06 40s/Female].

PHIM dimension 6: Routine adherence
We defined routine adherence as the amount of flexibility in scheduling when managing PHIM. High-on-routine adherence individuals observed a regular schedule of PHIM tasks. These individuals often scheduled PHIM-related tasks in advance and planned other life activities around the PHIM task schedule. High-on-routine adherence individuals often set a precise sequence of PHIM tasks to complete upon waking and around mealtimes. One participant described creating and following strict routine to support the requirements for different medications taken with or without food [SD02 60s/Male].

Low-on-routine adherence individuals were flexible in performing PHIM. These individuals described easily adjusting the scheduling of PHIM tasks. One participant described skipping a dose of medication if she remembered too late in the day [A03 40s/White/Female]. Low-on-routine adherence individuals were not concerned with precision. Instead, their focus was that the end-goal of the PHIM task was met. A participant who checked his blood sugar about once a week explained that he tested "whenever he feels like it" or "when he gets bored" [P113 60s/Male]. These individuals also described readily adapting PHIM tasks to fit changes in their daily routine. One participant reported taking nighttime pills "some time before midnight" [A01 60s/Female].

PHIM dimension 7: External cues
We defined external cues as sensory or environmental stimuli that triggered PHIM. High-on-external cue use individuals relied on visual or auditory stimuli in the environment, such as reminders from others or device notifications, as signals for PHIM. One participant described how she used color-coded pill organizers as a cue for when prescriptions need to be refilled [A05 60s/Female]. These individuals responded to alarms, reminders from friends/family, and seeing objects throughout the home. Another participant relied on morning television shows (e.g., the news) as a trigger for taking morning medications [A02 70s/Female].

Low-on-external cue use individuals relied on bodily stimuli and memory to trigger PHIM, such as pain or hunger. These individuals also used other activities as PHIM triggers. For example, one participant used the routine of taking morning prescription medications as a trigger to take his daily dose of aspirin [SD01 70s/Male].

Discussion

Our objectives were to identify individual differences in PHIM that can be used to inspire the design of tailored PHIM processes, products, and tools to support individual PHIM needs. Through an exploration of interactions between individuals' cognitive work of PHIM and how they distributed that cognitive work within the sociotechnical system, we identified seven PHIM dimensions that individuals use to support PHIM in the home. Our study expands on previous work by identifying individual differences in practice, operating across multiple dimensions of PHIM that shape and are shaped by the home environment in which PHIM is performed.[22,41] For example, results of the parent study show that individuals have a strong preference to use certain features of the home environment in specific places in the home to support their PHIM.[21]

The Context in which PHIM occurs inherently shapes PHIM
Our findings suggest that to design tailored processes, products, and tools to support PHIM, the study of PHIM must be expanded beyond the task level to include the context in which PHIM occurs. Recent research has recognized that PHIM both shapes and is shaped by the home sociotechnical system.[14] In other words, PHIM is inextricably linked to the home sociotechnical system in which it occurs.[14] Our findings expand upon this research to suggest that there are individual differences in PHIM, and in particular, individual differences at the person level interact with the context of PHIM. Thus, individual differences in PHIM must holistically capture the way individuals interact within the home sociotechnical system to perform PHIM. This is particularly critical to the design process in that the sociotechnical system must be considered in the design. That is, any change to the system such as implementing a new tool, affects all other aspects of the system.[42] If the system is not addressed as a whole during the design process, unintended consequences such as errors, frustration, and increased workload could lead to abandonment and low rates of acceptance.[43-45]

The potential of PHIM-typing
Perhaps not surprisingly given the current push toward precision medicine with efforts such as the "All of Us" Project, which seeks to tailor medicine to individual differences in lifestyle, environment, and biology; health services and health information technology research has recently begun to consider individual differences in patient's needs related to healthcare processes and tools.[46] For example, our findings parallel recent research indicating that individuals display different communication and interaction styles when using consumer HIT.[47-49] Further, the identified PHIM dimensions are supported by previous research pointing to the importance of discrete dimensions including privacy,[50-53] personal engagement

and guidance,[54] documentation reliance,[54] physical distribution,[54] and external cues,[55] and patient activation.[56] Our approach expands this research by providing a framework that can be used to examine the dimensions individually and as a holistic PHIM-type.

These findings represent a hypothesis-generating step in the identification of dimensions that comprise individual PHIM types. We propose PHIM-typing as the process of predicting a person's unique tendencies for performing PHIM based on where they fall along a continuum for each PHIM dimension. It is possible that certain PHIM dimensions may be predictive of other PHIM dimensions. Future research in this area should explore potential correlations and interdependencies of dimensions, establish construct validity, and develop a PHIM-typing survey tool that could identify different levels of expressions of the dimensions for individuals.

PHIM-Typing for design

PHIM-typing has the potential to mitigate the continued challenges associated with PHIM, and reduce consumer HIT abandonment by enhancing and inspiring the design of PHIM processes, products, and tools through individualized and adaptable design criteria.[7] For example, the process of design could focus on tailoring by user journey mapping for PHIM types and using PHIM-type based interfaces.

Potential design implications include tailoring healthcare professional information processes to an individual patient's PHIM type, selecting tailored discharge summaries and instructions based on a patient's PHIM type, designing mhealth applications that can be tailored to PHIM types (e.g., for high-on-physical distribution individuals, mhealth could activate GPS-enabled location-based notifications that are triggered when in certain areas), and employing machine learning to provide tailored resources to high-on-guidance individuals.

Limitations

Our study has several limitations that should be considered. First, our study was conducted with a small number of participants in only one region and at a certain time in history and technology acceptance. Their experiences may not be generalizable. Second, PHIM dimensions are not yet clearly delineated constructs and certain dimensions may exhibit overlap. Future work will seek to validate PHIM dimensions in larger samples, assess correlation and independencies of dimensions, and develop a PHIM-typing tool. Third, the vizHOME project focused on participants who were told they have diabetes, and results may be specific to people with diabetes. Finally, we did not capture information about the length of time since participants were told they have diabetes. Future work will explore the interaction between how long someone has had a chronic disease and their PHIM type.

Conclusions

By exploring interactions between PHIM tasks and the sociotechnical system of the home environment, we found that participants have seven dimensions for managing PHIM in the home. Identification of individual differences in PHIM can support the creation of human-centered design considerations for tailored environments, products, processes, and technologies that support PHIM. Future research will seek to validate PHIM dimensions in a larger population and develop a PHIM-typing measure to identify PHIM types toward tailoring processes, products, and to individual needs in context.

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