Artifact Usage, Context, and Privacy Management in Logging and Tracking Personal Health Information in Older Adults

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Consumer health information technology (CHIT) applications have the potential to improve overall care quality for older adults. The design and development of CHIT applications requires an understanding of the current and future personal health information management (PHIM) activities occurring in home and community settings. Building a better understanding of critical PHIM activities, such as how older adults track and log health information, is essential in the design of technologies that support these activities. This paper presents findings from a contextual inquiry of how older adults currently use artifacts in logging and tracking personal health information (PHI). Context and privacy management emerged as key themes in data analysis. Design implications for future CHIT applications are discussed.

"I use a calendar to document my appointments both health and lunch related. I have 2 calendars: one calendar near the telephone in the living room, which I list important information about upcoming appointments and another one in the kitchen, which I provide more information about what happened at the appointments and doctor information. I also write down what is important for future appointments [sic]." – ***88 year-old study participant***

INTRODUCTION

A recent report released by the Pew Research Center Internet & American Life Project (2013) states that 69% of U.S. adults keep track of at least one health indicator such as weight, diet, exercise routine, health indicators or symptoms. Adults aged 65 years and older are more likely to participate in these personal health information management (PHIM) tasks than younger adults (Fox & Duggan, 2013). Healthcare providers now more frequently demonstrate interest in helping older adults engage in PHIM tasks and healthcare activities, particularly as the healthcare needs of older adults shift from episodic to continuous care (Centers for Disease Control and Prevention, 2011; Microsoft ® HealthVault, 2011).

According to Fox and Duggan (2013), adults who engage in PHIM tasks such as tracking personal health information change their overall approach to maintaining their health, regardless of age. Adults tracking personal health information ask healthcare professionals new questions or seek second opinions, both of which influence an individual's decision about how to proceed in treating an illness or condition (Fox & Duggan, 2013). Fox & Duggan describe in the Pew report the methods by which adults currently track health information and discuss different ways in which adults perform PHIM activities. Common methods include tracking information mentally, on paper, and through some form of technology. While the Pew report highlighted technology use as a method for tracking health information, how technology is situated in day-to-day practices is still not well understood.

Many artifacts and tools currently support PHIM tasks and activities (Agarwal & Khuntia, 2009; Fox & Duggan, 2013). In fact, in our study older adults used both electronic and paper-based artifacts to track personal health information (PHI) in various locations outside a hospital setting, including the home, recreation center, senior center, social rooms, fitness center, retail pharmacy stores (i.e., Walgreens, CVS, Walmart Pharmacy), and other locations. Zayas-Caban (2005) studied PHIM between families and discovered that the same kind of PHI is distributed across multiple rooms in the home and stored in artifacts that afford different degrees of accessibility, visibility, and ownership.

However, current knowledge about the various locations and types of artifacts used to support PHIM tasks and activities are not sufficient to guide and inform design of future consumer health information technology (CHIT) applications. There still remain questions regarding how people in their natural settings use artifacts to perform PHIM tasks and activities. Although CHIT applications have the potential to enhance overall care quality among older adults, the design and development of such systems requires a better understanding of how artifacts are used to support PHIM activities in different settings. In this paper, we discuss artifact usage in the logging and tracking of PHI among older adults in non-traditional healthcare settings. The following research question is explored:

> *How do older adults currently use artifacts and tools to log and track personal health information in home and community-based settings?*

METHOD

Our exploration of this research question was informed by an Activity-Theory (Engeström, 1987; Leontiev 1981) approach, taking a holistic approach to understand activities such as the logging and tracking of PHI, and took the form of a contextual inquiry (Beyer & Holtzblatt, 1998). Activity theory thus shifts the focus of our research from

Table 1. Example Utterance from a Contextual Inquiry Interview

UTTERANCE	CODE	CODE DEFINITION
*"**I use a calendar to document my appointments both health and lunch related**.[1,2,3] I have two calendars – one **calendar near telephone in the living room,**[4,5] **which I list important information about upcoming doctor appointments**[7] and **another one in the kitchen,**[4,6] **which I provide more information about what happened at the appointments and doctor information**[7] including what is important for future appointments [sic]."*	[1]Type of PHI	Stating the health-related information that is logged or tracked.
	[2]Artifact usage	Stating the means by which the PHIM activity is executed.
	[3]Non-electronic artifact	Stating a non-electronic artifact (paper-based or other device) used to perform the PHIM activity.
	[4]Location within home	Referring to the location where information is logged or tracked within the home.
	[5]Location within home	Referring to the location where information is logged or tracked within the home.
	[6]Location within home	Referring to the location where information is logged or tracked within the home.
	[7]Privacy strategy	The process of differentiating the amount of PHI tracked or logged with artifacts, or using memory, for privacy.

human action to human activity, thereby allowing us to obtain a deeper understanding of the activity of logging and tracking PHI in older adults. Our contextual inquiry engaged older adults as partners in the design process through observations and semi-structure interviews conducted in the adults' homes, a community center, or a sensor center.

Participants

The study involved older adults residing in the Madison, Wisconsin area who were recruited via email, flyers, newspaper ads, and word of mouth. Adults were chosen to participate in the study following successful completion of a phone screening, which included questions regarding current health status, age, PHIM experience, education level, and residence. Only older adults who 1) were currently participating in PHIM activities; 2) resided in an apartment, house, condominium, townhouse or independent living facility; and 3) were willing and able to complete the protocol were eligible for this study. The study population consisted of 20 older adults (nine men and eleven women) ranging between ages 51 to 94, with a mean age of 70.1 years. Six of these adults were residents of an independent living facility, and 14 older adults lived in an apartment or single-family home. In addition, 17 older adults self-reported to have some computer or laptop experience, and 11 of the 17 own their own computer or laptop. All participants had a health condition, such as high blood pressure or high cholesterol, that they were managing and monitoring.

Procedure

Signed consent was obtained from each participant. Contextual inquiry interviews were conducted in the participant's home (40%), senior center (10%), or community center (50%), which represented places where older adults currently log and track health-related information. The researcher asked participants to perform and think-aloud a PHIM activity of their choice. Think-aloud is a research method in which a participant verbally explains a task or activity to the researcher. Each participant completed a visual questionnaire at the end of the interview. A visual questionnaire is a mapping diagram used in this study to describe what type, how much, and with whom older adults are willing to share PHI. Each contextual inquiry interview lasted approximately 60 minutes. The researcher made an audio recording of each interview session and photographed the layout of artifacts and the physical space in which they resided.

Data Analysis

We analyzed the field notes and audio recordings to identify phenomena related to our research question. We used the photographs to reproduce the layout of the home and document the types of artifacts used to complete PHIM tasks. Utterances segmented all interview and visual questionnaire responses. For this study, a participant's response to each interview question and the visual questionnaire defined an utterance. Participant responses were entered into a spreadsheet and coded using initial (open) coding techniques as described by Glasser & Straus (1967). A set of 50 codes emerged.

Each utterance segment was scored dichotomously (0= absent or 1= present) for evidence of the codes. Major categories emerged in creating affinity diagrams of coded utterances. These categories formed consolidated work models to describe PHIM among older adults. The participant response from an 88-year old participant appearing at the beginning of this article and in Table 1 is an example of a coded utterance.

Reliability Analysis

To ensure objectivity in the coding process, an inter-coder reliability analysis was conducted. The reliability coder received thirty minutes of training and coded 10% of the full sample of field notes and photographs using 50% of codes. The Cohen's kappa score between the two coders was .74.

Table 2. Type of Personal Health Information

PHI	Example
Vital Signs	Blood pressure level, cholesterol level, weight
Diet	Calorie intake, meal plans, nutrition facts
Exercise	Calories burned, exercise type, length/time
Medication	Dosage of pills & vitamins, prescriptions, time intervals
Doctor Related Information	Appointments schedules, doctor contact information, instructions (routine/emergency)
Instrumental Activities of Daily Living	Daily tasks/activities: shopping (all types), financial management, religious activities, housekeeping, work/volunteering, socializing, hobbies
Symptoms	Type & location of symptom, duration, pain
Other	Sleeping pattern, dates of illness, general health condition information, brochures

RESULTS

Overall Findings on Artifact Use

A number of health information types (see Table 2), artifacts that support tracking and logging of such information (see Table 3), and locations in which these artifacts were used (see Table 3) were observed in this study. Table 2 provides examples of the various types of PHI observed, which are consistent with previous work on consumers' PHIM (Civan, Skeels, Stolyar, & Pratt, 2006; Moen & Brennan, 2005; Zayas-Caban, 2005). Two main groups, non-electronic and electronic, classify the artifacts observed in our study: Some examples of non-electronic artifacts include: pillbox, calendar, daily journal, notebook, and printout. Electronic artifacts include blood pressure monitor, scale, exercise equipment, spreadsheet, word processor, and computer application. Figure 1 presents photographs of some artifacts observed during the contextual inquiry interviews. Table 3 lists the location in which each artifact was found. All the artifacts (except the puzzle book) were observed in the home setting, while a subset of artifacts was observed at the community center. Calendars and daily journals were observed most frequently across locations.

Use of Memory for Logging and Tracking

Although older adults used electronic and non-electronic artifacts to log and track PHI, most of them also used their memory. This finding is consistent with the logging and tracking practices described in the recent Pew report (2013). In some cases, both memory and an artifact recorded PHI; however, multiple interviews across locations show that several times only memory is used to log and track PHI. Participants described memory usage as either a tool or privacy strategy (see Table 4). An older adult used memory as a privacy strategy to prevent unintended disclosure of PHI. In this study, we found that memory was used as a tool to compensate for some of the problems that accompany artifact usage. The participants who used only memory to log and

Table 3. Observed Artifact Locations

Artifact or Tool	Home	Community Center	Work	Senior Center
Blood Pressure Monitor	✔		✔	✔
Calendar	✔	✔	✔	✔
Cell Phone	✔			
Computer (MS Word or Excel)	✔	✔		
Computer Application – CHIT	✔			
Electronic Personal Health Record	✔			
Loose Leaf Paper/Post-It Notes	✔	✔		
Notebook/Binder/ Folder/Journal	✔	✔		
Pillbox	✔			
Puzzle Book		✔		
Scale	✔			
Speedometer	✔	✔		

PHI expressed that they had no need for an artifact, because they were their own caregiver and therefore also the only person apart from healthcare professionals who would need to access the information.

Our qualitative analysis revealed several other reasons why older adults do not use an artifact to track their health information:

1. Tracking interrupts daily routine
2. Time intensive
3. Difficult to use technology
4. Tracking information in certain places is inconvenient
5. Want to avoid thinking about their health condition
6. Do not like to write or cannot spell
7. Does not like to keep track of different pieces of paper or use more than one artifact for logging and tracking
8. Fear of losing information or not being able to find information at a later date

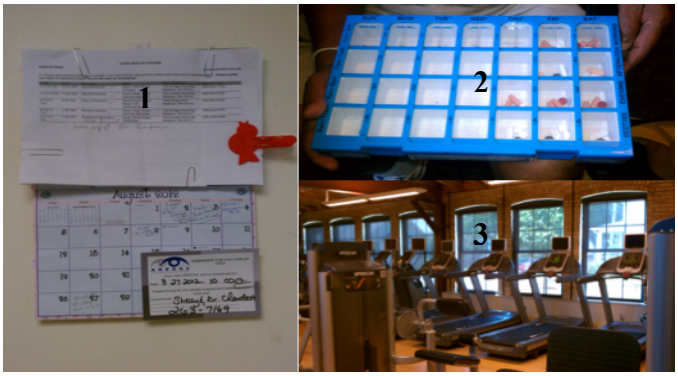

Figure 1. Photographs of artifacts used in a logging and tracking personal health information: 1) a calendar with doctor appointment summaries posted on the kitchen wall, 2) a 28-day pillbox which was kept on the living room table, and 3) exercise equipment in the gym at the community center

Table 4. Excerpts about Memory Usage

Memory: Tool	Memory: Privacy Strategy
"My memory is my computer. I keep everything in my mind as it relates [sic] to my blood pressure and cholesterol levels." – ***73 year-old study participant***	*"I have always watched what I eat because I was concerned about weight or diet, but I have never written the information down. I use my memory to collect it. It's for my personal use."* – ***94 year-old study participant***
"I want to see how fast, the number of miles and how long I walk or bike; but I don't write this information down. I keep monthly information about walking and biking in my memory." – ***58 year-old study participant***	*"I keep own status in mind because I am the only taking care of myself [sic]."* – ***66 year-old study participant***
"I don't write my exercise down, because it messes up or interrupt [sic] my routine. I notice symptoms such as swelling of the foot but I don't write it [sic] down. I refer to doctor's instructions and take recommended medication as instructed. I use my memory to track almost everything." – ***69 year-old study participant***	*"I don't keep information about how long or how far I walk. I just make sure that I can say I did it for the day so I use only my memory to track it."* – ***88 year-old study participant***

Distributed Logging and Tracking for Privacy

The use of multiple calendars to log and track health-related information was a major category that emerged during the analysis, although none of the participants used a digital calendar to log and track information. "Doctor related information" was the most common type of PHI seen on older adults' calendars. In most cases, calendars were used to collect the same personal health information in addition to other information such as lunch appointments, daily tasks, due dates for bills, and so on. The amount of information disclosed on a calendar changed with calendar location (see Figure 2). For example, a calendar in the living room might include a doctor's name and appointment time, while a calendar in the bedroom would include the same information along with the reason for the appointment. In a few instances, calendars separated PHI from other aspects of life, as illustrated in the excerpt below:

"I use a separate calendar to coordinate doctor appointments. I keep the calendar on my desk in the bedroom. I enter doctor's name, number and reason for appointment. The calendar also includes information about other non-medical appointments. The second calendar is up on the wall in the living room and includes information about family and friends' birthdays." – ***73 year-old study participant***

Further analysis revealed that older adults controlled PHI content written on calendars by calendar location as a type of information privacy control strategy. Particularly, PHI tracked in public areas such as the living room was minimal, while PHI recorded in private areas such as the bedroom contained more detail.

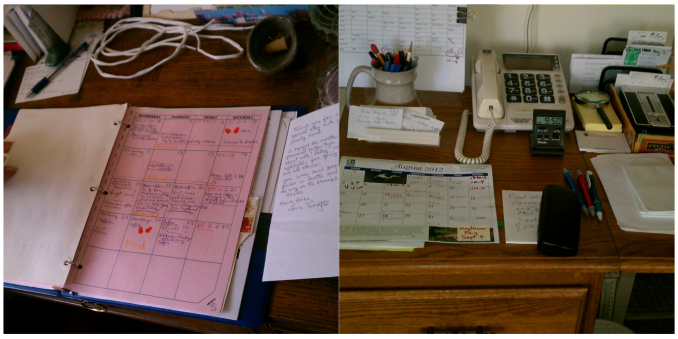

Figure 2. Pictures of artifacts a married couple use to track PHI and daily tasks: The couple uses two calendars found in two different locations within their home. The picture on the left is a calendar kept in a binder on a bedroom work desk This calendar includes detailed information about tasks and appointments. The picture on the right is a calendar located on a work desk in the living room. This calendar includes more general information.

Some older adults complemented a calendar with a notebook or daily journal, which allowed for more detailed PHI than the calendar alone. Figure 2 and the excerpt below demonstrate the privacy strategy used by older adults who log and track PHI using two calendars within the home environment.

"I keep appointments by the phone in the living room. They are written in red so I know where it [sic] is on a daily calendar. I keep another calendar that lists more information about where we go and daily tasks on my work desk in the bedroom. We place notes down on the floor the night before to remind us what has to be done the next day."– ***84 year-old study participant***

Data analysis revealed that context and privacy control strategy were associated with calendar usage for logging and tracking PHI among older adults. Calendars were used in the kitchen, living room, bedroom, and work environment; however, the amount of information disclosed on a calendar changed based on location. Older adults who used a calendar to log and track PHI in other areas within or outside the home also employed a privacy strategy. For example, we found that calendars located near a door or in a community center, for example, contained more general information.

DISCUSSION AND CONCLUSION

This study confirms and extends Fox & Duggan's (2013) findings regarding older adults' use of electronic and non-electronic artifacts and their memory to log and track PHI. Like the Pew report (2013), our study shows that memory is the preferred medium for older adults who log and track their PHI, and that memory is followed by non-electronic artifacts and then electronic artifacts in frequency of use. However, our study extends previous work by identifying the physical and social-contextual influences on artifact use as it relates to the logging and tracking of PHI.

Calendars and daily journals were the most used non-electronic artifacts. Most participants recorded information on two calendars or one calendar supplemented with a daily

journal. Older adults logged and tracked information related to doctor's visits in addition to daily tasks, including the instrumental activities of daily living, on these artifacts. There were few cases where separate calendars were used to collect PHI and track non-health related information such as birthdays and due dates for bills.

Calendars give older adults an all-in-one tool and provide features and flexibility that are not yet provided by current digital calendars. This study demonstrates that older adults like to control the amount of PHI made visible to others based on the location of a calendar. Their practices involve using multiple calendars located throughout a home or other natural setting to control privacy. This finding suggests that digital calendars might be designed to support these existing practices. Current digital calendars are designed primarily to meet general use needs, and privacy controls are implemented through passwords. The use of passwords might not fit well with the expectations and practices of an older adult user group who is logging and tracking PHI. Designers need to consider other ways to control access and protect the PHI logged and tracked by older adults if digital calendars are to be used to record PHI. Also, current calendar systems do not change the amount of information visible based on location. Although limited information is displayed in the "day, week, or month" view, once a user clicks an event, all event details are displayed. New digital calendars should incorporate a feature that allows information presented to change based on location.

Older adults also identified their memory as a tool used to track PHI. They often used their memory in conjunction with an artifact; however, memory tracked more sensitive information such that memory was used a privacy control strategy. It is important to note that some older adults used their memory to track their PHI only for convenience. Older adults' use of memory to track health related information has both advantages and disadvantages. While, "tracking by memory" does not interrupt daily routines with the need to locate and engage an external artifact, the information stored might be forgotten. The pervasive strategy of relying on memory suggests that future CHIT applications will need to be as seamless as tracking with memory (Fox & Duggan, 2013). Future digital calendars may include a mobile, voice-based entry system that does not disrupt ongoing activities but captures data when needed. The older adult would have the opportunity to review the entries and make necessary adjustments. Future calendars could also include a feature that auto-groups or generates a list of related entries when an older adult begins to enter information. The group or list would remind older adults about previous entries and improve long-term tracking.

There is an emotional component to this study that requires further exploration. One reason that older adults did not want to track PHI was that they wanted to avoid thinking about their health condition, as there is an emotional cost in being reminded about one's health condition. This finding has substantial implications for the acceptance of ubiquitous computing in healthcare and the sharing of PHI. Designers will need to incorporate features that consider the emotional impact of tracking and logging PHI. As found by a recent study on the design and development of a device to motivate medication management, emotional considerations critically influence a patient's motivation to accept and adhere to the use of future CHIT (Chiou, Venkatraman, Larson, Li, Gibson, & Lee, 2013).

Designers must be careful when trying to replace a non-electronic artifact with an electronic artifact. Sometimes the replacement inadvertently undermines the activity system; for example, developing a home-based care coordination system using the current features of digital calendar systems will not meet the needs of older adults who control information content based on location to manage their privacy. The limitations of non-electronic artifacts coupled with current privacy management strategies employed by older adults, warrants more research to inform the design and development of future CHIT.

Our future work involves drawing on these design implications to design, prototype, and evaluate a ubiquitous computing system that supports the health information tracking and logging practices and privacy management strategies of older adults.

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