Ageing Int (2011) 36:232–252
DOI 10.1007/s12126-010-9083-y

Privacy, Technology, and Aging: A Proposed Framework

Lesa Lorenzen-Huber · Mary Boutain · L. Jean Camp · Kalpana Shankar · Kay H. Connelly

Published online: 2 December 2010

Abstract The purpose of this study was to develop a privacy framework that could inform the development, adoption, and use of home-based ubiquitous technologies for older adults. We began with a five-part privacy framework, derived from the literature, and tested it through a qualitative exploration of older adults' perceptions. Focus-group sessions were conducted with 64 community-dwelling older adults. Transcriptions were analyzed using a grounded-theory approach. Major and minor coding themes were identified, refined, and expanded upon, and transcripts were then coded using these themes. Participants' concerns about privacy were more contextualized than our previously defined framework. Factors that influenced perceptions of privacy were identified as perceived usefulness, the importance of social relationships, data granularity, and the sensitivity of activities. Elders' perceptions of privacy relative to the development, adoption, and use of home-based ubiquitous technologies are highly contextual, individualized, and influenced by psychosocial motivations of later life. Data analysis and gerontological theory informed the expansion of our initial framework into a new framework that considers perceived usefulness, key social relationships, data granularity, and sensitivity of activities as factors relevant to the use of in-home technologies. As elders' naïve mental models lead to a perception of risk that may be less than actual risk, technologies should enable user-centered transparent data control. Transdisciplinary theories of privacy and aging can inform the development of a privacy framework for home-based technologies that can contribute to an optimal life in old age.

Keywords Aging · Technology · Adoption · Privacy · Autonomy · Social motivation

L. Lorenzen-Huber (✉) · M. Boutain
School of Health, Physical Education, and Recreation, Indiana University, 2805 E. 10th Street, Bloomington 47408 IN, USA
e-mail: lehuber@indiana.edu

L. J. Camp · K. Shankar · K. H. Connelly
School of Informatics and Computing, Indiana University, Bloomington 47408 IN, USA

There is no question that information technology is increasingly pervasive. In less than a generation, networked computers and mobile phones have connected us to friends, music, events, and information in ways unforeseeable 25 years ago. We can only imagine the kinds of technologies that will be in our lives and homes 25 years from now. Will they be as beneficent as we imagine our technologies are today? Or will the aggregation of all the personal data collected by these devices challenge personal information privacy? Since many technologies are being designed to help older adults age in place, an understanding of older adults' perceptions of risks related to data sharing is critical. What theories of aging can help to explain older adults' unique vulnerabilities to infringements on personal privacy from technologies installed in the home?

Trends in health care services suggest an increased need for technologies that support older adults living independently in their homes. Currently, 80% of older adults in the United States have been diagnosed with a chronic health condition, and 50% of those have two or more chronic conditions (Centers for Disease Control and Prevention 2010). The Centers for Disease Control and Prevention estimate at least 34 million people provide unpaid caregiving services to friends and family members over 50 years of age. This number will continue to grow as the baby-boomer cohort ages and chronic disease rates increase. In the United States, administrators of government-managed health care programs, private-sector insurance and medical providers, and policy makers increasingly look for ways to reduce skilled nursing costs by expanding home and community-based services for older adults and people with disabilities. In order to improve quality of life and health for older adults, the CDC recommends the promotion of caregiving interventions. Technological advances are assumed to play a large part in assisting these adults through the development of personal devices and home-based technologies.

Recent studies by Beach et al. (2008) and Tomita et al. (2007) indicate that interest in adoption of technology by older adults is driven by utility. Results indicated that a demonstrated need to use the technology was a primary focus of older adults testing the technology. Other studies (Melenhorst et al. 2006) found understanding perceived benefits of the technology was important in successful adoption of an intervention. Czaja et al. (2006) suggest that cognitive abilities, computer self-efficacy, and computer anxiety play key roles in technology adoption.

However, much of the research on technology for aging in place has not been adequately informed by theories of aging, and most current frameworks for privacy do not sufficiently address the intersection of aging, technology, and the home (van Bronswijk et al. 2008; Cantor 2006). These are gaps we begin to address in this paper. The primary purpose of this study was to develop a privacy framework, informed by theories of aging that is useful for developing home-based ubiquitous technologies and sensitive to the privacy concerns of older adults. More than 60 older adults toured a "Living Lab," a real home with prototypes installed in situ. Small groups of three to four older adults learned about the each prototype, then came together in semi-structured focus group sessions of approximately 15 people. The sample was deliberately comprised of likely "early adopters," from a university-affiliated retirement community and other community-residing older adults. This sample was chosen because the scale of this preliminary research was necessarily limited. "Early adopters," (defined as a little younger than average, higher-than-

average income and education, and high participation in formal activities) are likely to have high technology self-efficacy, but just as likely as non-early adopters to face age-related declines for which home-based ubiquitous computing (ubicomp) is a valid choice. A description of the prototypes used in this study is provided in Tables 1 and 2. A qualitative approach using semi-structured focus groups and guided by grounded theory was used to analyze the data.

Literature Review

As countries around the globe search for ways to meet the challenges of aging populations, transdisciplinary research is critical for developing theories linking gerontology to subject domains addressing real-life problems (Achenbaum 2010). Theories about the social constructivist nature of privacy are in flux; the swift evolution of social networking provides new questions about, and challenges to, personal privacy every day. To date, much of the literature about privacy references Westin's typologies (2001). While his typologies might be applicable to younger adults navigating the privacy policies of Facebook, research on privacy, technology, and older adults so far (Wild et al. 2008; Kwasyn et al. 2008; Courtney et al. 2008) suggests his theory does not accurately describe older adults' views of privacy. Nor are static models particularly useful in explaining the dynamic, highly contextual nature of relationships, information, and technologies (Nissenbaum 2004). The findings from these studies suggest that older adults are unconcerned about privacy related to data collection and sharing. One likely explanation is that older adults' have relatively naïve mental models about technology; their perceived risk is very likely much less than their actual risk. Since concepts of data sharing, aggregation, and mining are relatively unfamiliar to most older adults, they underestimate the importance of protecting the privacy of their personal information. In short, they tend to equate "private" information with "secret" information, which is not necessarily useful in protecting informational privacy or managing data in pervasive applications.

But not all older adults are so naïve. Even after potential consequences of aggressive data sharing are explained, older adults seem surprisingly unconcerned. The one area of exception we found is financial data; older adults in this study were very interested in maintaining control over financial data and avoiding identity theft. However, research so far suggests that older adults have little to no concern about

Table 1 Dimensions of initial privacy framework

Dimensions	Description	References
Seclusion	The right to be left alone	Warren and Brandeis 1890
Autonomy	The right to self determination	Introna 2003
Property	The right to determine uses and dissemination of personal data	Bloustein 1968
Spatial	The right to determine physical and virtual boundaries	Odlyzko 2004
Data Protection	Data is transparent, verifiable, and correctable	

Table 2 Prototypes used to explore five domains of well-being

Technology	Health	Safety	ADL	Social	Financial
MD2: Internet-enabled medication dispenser that sends alerts if a medicine is not taken at the appropriate time (commercial product)	X				
MindFit: games to promote cognitive health (commercial product)	X				
Wild Divine: bio-feedback game aimed at reducing stress (commercial product)	X				
Mirror Motive: mirror that displays reminders (e.g. medicines) and coordinates social engagement when person is detected nearby	X			X	
Portal Monitor: real-time digital photo alerts sent to a caregiver's cell phone whenever the doorbell rings or the front door is opened		X			
Ambient Plant: plant pot with sensors and lights to facilitate awareness between remote family members. When a person is in the proximity of their plant, the remote pot conveys this activity by turning on its lights.			X	X	
Presence Clock: clock with sensors and lights to facilitate awareness between remote family members. Similar to the Ambient Plant, but also shows a history of activity levels (the last 12 h).			X	X	
Ambient Trust Cube: cube that sits next to a computer and pulses different colors depending the trustworthiness of an Internet site					X

sharing information about personal health, daily activities, and social engagements with family and health care professionals. It is only after a review of the findings through the lens of theories of late life that the need for a privacy framework applicable to late life becomes apparent.

Theories of social motivation in late life suggest that older adults' complacency about privacy could be driven by the prioritization of important relationships (Carstensen et al. 1999). However, that does not mean that we can ignore privacy considerations for older adults. An elder-sensitive privacy framework will inform the development of home-based technologies by increasing data transparency, incorporating privacy awareness, and providing user-friendly control over personal data.

Initial Privacy Framework

The purpose of this study was to develop such a framework. We began our study with a five-part privacy framework based on the literature. Our initial framework included privacy as seclusion, or "the right to be left alone" (Warren and Brandeis 1890). A constantly "on" monitoring system in the home, for example, would violate this construct if it could not be turned off. The second concept was privacy as autonomy, or the right to self-determination. Most U.S. Constitutional definitions of privacy encompass some form of autonomy and its effects. Autonomy is violated if a person's activities are curtailed, or if the person perceives or fears curtailment and

thus does not engage in those activities (Introna 2003). Privacy as property is the right to determine the uses and dissemination of personal data (Bloustein 1968; Mell 1996). The use of demographic information to enable price discrimination, for example, can violate this dimension of privacy (Odlyzko 2004). In pervasive computing environments, privacy is often constructed as a spatial construct, with an emphasis on physical and virtual boundaries (Odlyzko 2004; Jiang 2002; Langheinrich 2002; Boyle 2003). Finally, data protection makes data generated by a home-embedded sensor network transparent, verifiable, and correctable to the individual. Acknowledging that other framings of privacy are possible, we began with these as particularly germane to home-based technologies.

Social Motivation in Late Life

Along with our initial privacy framework, we began with an understanding of the psychosocial needs and motivations in late life. Carstensen's Socioemotional Selectivity theory suggests that the notion of time plays a critical role in ranking behaviors. Carstensen's theory states that diverse social goals can be classified into two broad categories: knowledge acquisition and regulation of emotion (1999, pg. 166). Those individuals with an expansive sense of future tend to pursue knowledge-related goals while those who sense a shorter future focus on present orientation that relates to emotional meaning and experiencing emotional satisfaction. Socioemotional Selectivity theory suggests a trend across the lifespan from knowledge acquisition to emotionally related goals. This theory predicts "that endings are associated with qualitative changes in emotional experience" (pg. 168). Carstensen explains this may be due in part to the presence of tighter social networks and behaviors related to satisfaction of emotional needs. This suggests that older adults who are closer to the end of their lives are more concerned with emotional connections with friends and family and may show little interest in understanding new technologies or concerns about data privacy due to their focus on the present and need for meaningful experiences with loved ones.

Independence and Autonomy

Besides prioritizing meaningful relationships, older and disabled adults are deeply concerned about independence and autonomy. A seminal work by Sixsmith (1986) suggests a perception of independence is comprised of multiple dimensions (p. 341):

1) Being able to look after one's self; not being dependent on others for domestic, physical, or personal care—physical independence
2) Capacity for self-direction, free to choose what to do, free from interference, and free from being told what to do—autonomy
3) Not being under an obligation to anyone, and not having to rely on charity. Independence is not threatened if support is based on reciprocity or interdependence.

While the need for autonomy and independence may be culturally influenced, most older adults prefer to maintain reciprocal exchanges over dependence as a way to build social capital (Keyes 2002). Carstensen's Socioemotional Selectivity theory

and Sixmith's definition of autonomy and independence suggest that older adults are likely to prioritize relationships, independence, and autonomy over vaguely understood constructs such as data privacy. In developing a privacy framework relevant to home-based technologies for older adults, it is essential to understand and address these dimensions in order to support the development of technologies that protect and enhance quality of life.

Methods

Design of the Study

We began with these deceptively simple research questions:

1) Is our initial privacy framework valid for developing home-based ubiquitous computing technologies?
2) Does the privacy framework accurately and adequately express the privacy concerns of older adults?

To tackle these questions, we chose a qualitative approach. Previous research studies have successfully used semi-structured focus-group sessions and grounded theory analyses to explore older adults' perceptions of privacy related to technology (Kwasyn et al. 2008; Courtney et al. 2008). To develop the protocol for the focus groups for this study, an initial series of hypothetical scenarios of older adults using home-based technology was developed. The purpose of the scenarios was to help elders imagine being in a position of needing some type of assistance to maintain their independence. The scenarios were refined through the use of the Delphi technique with a focus group of gerontology faculty and professionals from around the state. Several pilot tests were then done with small groups of six to eight older adults. The findings from the pilot tests were used to refine the focus group questions and methodology, concentrating on eliciting concerns of privacy, security, and other ethical considerations, rather than the usability of the technologies.

We also considered the context in which the focus groups would take place. We expected that respondents would be most able to visualize the prototypes and understand their uses if they were displayed in a naturalistic setting. The study was conducted in Indiana University's Living Lab, a real house which serves as a laboratory for aging-related technologies. In this environment, elders could interact with the prototypes as they would be used in the home and ask questions of researchers. Each room (kitchen, living room, sunroom, dining room) had a single, functional prototype so that we could have multiple elders interacting with different prototypes simultaneously, without distracting each other. The study was approved by the Indiana University Institutional Review Board affirming that the study would be performed in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki.

Participants

Participants (n = 65) in the focus groups ranged in age from 70 through 85. They were recruited through presentations at a local retirement community and university

alumni events. Forty-two were female, similar to the general population for this age group. Most (59) had adult children, with almost half having children living nearby. Eighteen participants were married; the rest (43) were widowed, divorced (1), or single/lived alone (3). All were mobile, healthy, and cognitively high-functioning. Ninety-eight percent (64) had attended college and six had graduate degrees. Most of the participants (57) were recruited from a local, affluent retirement facility; most lived independently in cottage-style housing or apartments, but could take advantage of the central dining facilities and social activities. The rest were living independently in the community. A preliminary anonymous survey was administered to the group to obtain demographic information and participants' familiarity with and interest in using various common technologies, both for communication and personal safety. Most participants were familiar with at least some form of information technology (computers, cell phones, etc). A small minority used a medical alert bracelet or other personal-safety monitoring device; only a few had experience with any other monitoring or other home-based technologies.

Prototypes

We selected eight technologies and prototypes that allowed us to explore a wide range of ethical issues with the elders. We selected three off-the-shelf technologies, and designed five specifically for the project, as summarized in Table 2.

We used three selection criteria to choose these technologies:

Utility Technology acceptance models and theories indicate that the perceived usefulness is the primary factor in user acceptance (Geraci 2004; Davis 1989); thus, we have selected technologies that address the different needs of elders. We identified five major domains in which technology could support independent, active aging: financial, social, health, daily activities, and physical security.

Data Types We selected technologies that collect different kinds of data and use the data in different ways in order to test the five-part privacy framework. We chose technologies that would facilitate more general discussion of technology use and ethics as opposed to usefulness. A particular concern was that as technology is designed for the home, it is becoming more and more integrated with everyday objects. This integration can lead to *invisible* data collection and use, a serious issue when addressing privacy concerns.

Aesthetics While acknowledging the prototypic nature of some of our devices, we endeavored to approach design and use with some consideration for look and feel since prototypes and devices were designed for use in the home. We selected technologies that didn't look like computers, but were embedded in everyday, household objects.

Data Collection

Five separate groups of participants, each group composed of approximately 15–20 participants, attended focus-group sessions at the Living Lab during a two-month

period. Following informed consent and a brief introduction, small groups of two to four older adult participants rotated through each room in the house. They were introduced to the prototype by a researcher, allowed to ask questions, and interact with the prototype. The conversations with the researchers were video and audio taped for later transcription. After approximately 10 min, they moved to the next prototype. When the participants had seen all prototypes, we brought the whole group together to ask more explicit questions about their privacy concerns and presented them with the scenarios to test the privacy framework. These larger focus-group sessions were audio and video taped and field notes were taken. After each focus group, the research team participated in a debriefing process which was also recorded. After key qualitative results were identified, the research team visited the retirement community to present the findings as a member check, confirming that the findings adequately captured the meaning and intent of the focus group participants.

Data Analysis

Data were analyzed using a grounded-theory approach. Audio tapes were transcribed and researchers independently developed major and minor coding themes. The research team then met to discuss areas of congruence and contention. After a series of weekly meetings to confirm interrater reliability in coding and discussion of coding themes, a code book with 13 major themes was identified, refined, and agreed upon by the research team. Transcripts of all the sessions were then coded using this code book; themes were refined and expanded upon as the coding proceeded. Each transcript was coded by two different researchers and then reviewed by the group to enhance validity. Following open and then more-focused coding, conceptual maps were created (Miles and Huberman 1994). Coded transcripts were then entered into NVivo, a qualitative data analysis software program. Eight of the 13 major themes were used in this analysis: (a) usability, (b) utility, (c) personal autonomy, (d) technology as replacement, (e) social implications of technology, (f) perceived vulnerability/personal concept of aging, (g) functional types of technologies, (h) privacy and technology.

Results

Privacy Framework Revisited

This study was designed to explore the validity and relevance of our initial privacy framework in developing home-based ubiquitous technologies for older adults. It quickly became apparent during the sessions that the participants in the study had little to no concern about any of the five types of privacy as constructed in our initial framework: seclusion, autonomy, property, spatial, or data protection. They also had naïve mental models about information privacy in general: what kind of data was collected, where the data were stored, who had access to the data, or what the data could be used for. These were concepts that were foreign, vague, or just uninteresting to most participants.

While they were relatively unconcerned about the informational privacy that might be abrogated by these monitoring technologies, they did provide rich

contextual data on the intersections of aging, technology, and privacy. Through repeated analyses of the data and through discussion in weekly research meetings, four overarching constructs emerged as a privacy framework relevant to older adults and home-based ubiquitous technologies. First, devices that were perceived as useful were generally viewed as acceptable, and privacy concerns about adopting such prototypes (e.g. the MD2, MindFit, and Portal Monitor) were low. Perceived usefulness, however, was predicated on awareness of current perceived personal vulnerability rather than preventative use against a future need. Second, the interaction of technology and primary relationships had a multidimensional effect on privacy concerns. While the importance of key relationships was generally more important than technology or privacy, older adults in the study expressed the desire to maintain autonomy and independence as long as possible. They expressed a desire to control decisions about what information was provided to which adult child caregiver, and to participate as equals rather than passively monitored subjects in information exchanges. Third, the granularity of the data affected the degree to which participants felt that the devices were acceptable or privacy invasive. Finally, certain activities were viewed as more privacy sensitive than other activities, and spatial concerns were trumped by the range of activities elders expected to be doing in the space. We use examples from the transcripts to illustrate each of these findings and then discuss the implications of a contextually sensitive privacy framework relevant to older adults and home-based ubiquitous computing.

Perceived Usefulness

Results from this study support technology-acceptance models' suggestion that usefulness is a primary concern of older adults in considering technology adoption. Participants were much more interested in discussing the usefulness of the prototypes than possible infringements on privacy. Usefulness was often predicated on perceived personal vulnerability and critical event, rather than daily monitoring.

Perceived Vulnerability

Many participants expressed a lack of desire to use the demonstrated devices because they personally did not have need of it or did not perceive a need of it. For instance, when participants were asked what they thought about the medication dispenser, their answers were based on whether they personally needed it or not. Participants often perceived a technology as beneficial for someone they knew, but did not feel personally in need of technological assistance, despite admitting to personal health challenges. "I think that the medication dispenser….. my brother-in-law takes about 12 different kinds of medications and they're all trying to single them out, so this would be wonderful for him for them to be processed like that." These same participants would mention in the next breath that they themselves took numerous medications, yet they did not seem to perceive an immediate personal vulnerability about medication adherence and thus indicated that they had no interest in the device.

Interestingly, they recognized *other* older adults' lack of awareness of vulnerability, "The problem is getting someone to admit it (that they should not be

living alone).” Another participant noted, “So many people come to our (retirement community’s) open house and say, ‘I’m not ready’ with a walker or what have you.” Even though study participants may have admitted to a fall in the past year, most felt that they personally were not in need of technologies such as the Presence Clock, which could indicate a possible fall.

Critical-Event Monitoring

Most seemed to think monitoring technology was more valuable for detecting accidents and emergencies, but less valuable for daily monitoring, “It seems to me that what I’m bothered about is being able to discriminate between the normal exceptions of life and something really serious. Before I came here (to the retirement community), I had two friends in two different situations, one who actually collapsed on the floor and nobody found her for 3 days. She got pneumonia and was really… This technology might be kind of useful…Before I came here I had the Medicalert. If you’re able to press a button that’s great and would eliminate the need for any of this technology. But if you have a stroke or a heart attack then you can’t press that button. To me it’s a question of having a technology that would pick up something major but wouldn’t be interrupting someone every time you did something different.”

To facilitate participants’ ability to look beyond their own personal, perceived vulnerability, we used hypothetical scenarios of older adults—developed through our pilot tests—who could benefit from home-based technologies. Participants were more likely to allow that the prototypes were useful for a hypothetical older person who needed some type of assistance to remain independent rather than for themselves.

Interactions Between Relationships, Autonomy, and Privacy

While perceived usefulness was the most important factor influencing perceptions of the prototypes, participants’ comments about the interactions of the technologies with family and friends suggested the importance of social relationships in later life. The complexity and heterogeneity of the comments also indicated the delicate negotiations needed to balance preferred levels of support, contact, autonomy, independence, and privacy.

Importance of Key Relationships

A number of participants were willing to adopt technologies if an adult child or other family caregiver wanted them to. They expressed interest in reducing any perceived burden of caregiving while improving communication and information sharing. They were also concerned about not being intrusive. Many worried that the sheer volume of data coming from the prototypes would be an intrusion into their already-busy adult children’s lives. The maintenance of the relationship was more important than maintenance of privacy. "I am very compliant about these kinds of things. I am not compliant with the thoughts of my mind, but I am compliant about following directions [from my adult children]."

Maintenance of Personal Autonomy and Independence

Most noted that using or adopting the technologies depended on the relationship between the older adult and their adult children. When asked if a prototype might help people stay longer in their homes before the children made them move, an elder said, "Oh, any method that they would agree to," suggesting the delicate balance between nurturing satisfying relationships while maintaining personal autonomy for as long as possible.

Other respondents suggested that a trade-off may exist between autonomy and privacy. "I think a lot of that depends on how badly you want to stay in your homes remotely, and your family's opinion on that too. You'd have to come to an agreement. You give up some of your privacy and give up some of these things in order to stay where you are." Others feared giving up control over their decisions to family members: "You are an independent person and when you turn over some of the decisions and have to rely on someone else, you're going to feel like a child. And you've been the adult the whole time …And the anxiety when you get to that point you know some day they're going to do something that you won't like and they're going to be more powerful than you are and you're going to have to succumb to their decisions." Another added, "It's the privacy thing. How much control do you want to give up. It's going to be hard enough when you're older to keep what little sense of self-dignity, and everybody I think is concerned as we get older how much—don't take my car. Whoa."

Of course, the decision to adopt technologies might be made by someone other than the older adult. Family and professional caregivers might be instrumental in suggesting the adoption of home-based technologies, particularly in the case of dementia. Many participants agreed that cognitive decline would be a reason for others to take control of their decisions, however participants admitted that self-perception of how to evaluate that is complicated. "Uh, I think that's a trickier one than the physical condition. At what point is a person willing to admit that they are slipping." In regards to a question about whether their children could have access to the collected data without their permission, a participant stated that only in cases of cognitive decline would that be acceptable. As a participant noted, "(I would want control over my information) unless I was mentally infirm."

Data Recipients

Older adults were selective about who would receive the collected data. "There's not a yes/no, black/white answer….who has the information, what's the nature of the information that I would trust Jane (daughter) with very much but wouldn't trust my daughter-in-law with very much. Would it be the same information? Selecting who these people are and having a feeling about how they would respond hits me." Information collected from the bedroom or bathroom was naturally viewed as more sensitive, and respondents were more selective about potential recipients of such information.

Technology Should Not Replace Human Contact

Some participants expressed a fear that the technologies would further shrink personal care and contact. "Some people like to be social, and if they can't get out of

the house, people (caregivers) coming in is nice." Another said, "I would much prefer someone coming by every day and giving me my medication and reminding me. I feel this is personal. They find out what kind of shape you are in."

Several participants recognized that there might be a limit to how long technology could replace personal care and support independent living. "If you get to the point that you need a device to take your pill, maybe you ought to be in a place where there is someone there," said one participant. "I could see someone who had all that, if they are so far gone that they need something like that then they're not going to be easy to teach how to use it correctly, and teach how they're going to be able to do something if there is a guy with a ski mask at the front door. I'm saying, why go to all this trouble when the person is not capable of acting on it?"

Reciprocal Exchange

The ambient plant and the presence clock are bidirectional. That is, not only can the informal caregiver see the activity levels of the older adult, but the older adult can see the activity levels of the informal caregiver. We used these prototypes to explore if the technology was more acceptable to elders if they were full participants in sharing data—both giving and receiving information about daily activities. This feature provoked mixed reactions. While some older adults enjoyed the reciprocal nature of these prototypes, which could give them insights into their children's lives, several were uncomfortable with asking their adult children to permit this. The older adults felt that they might be intruding into the lives of their adult children, suggesting that the social motivation to maintain mutually acceptable levels of support, contact, and autonomy are key factors in understanding older adults' views of privacy.

Data Granularity

The portal monitor, presence clock, and ambient plant allowed us to explore the issue of data granularity with participants. Generally, in-home technologies are designed to collect, compile, and communicate the most minimal amount of data, with the least granular data being preferable. In contrast to high resolution, always-on video, the portal monitor only captured three photos if the door was opened, and the plant and clock provided only an ambient indication of presence. Participants were generally opposed to highly granular data collection such as video, connoting it with being watched, or the equivalent of being "in prison." However, a simple indication of presence through the plant was perceived as often not providing enough information or accurate information. Participants noted that a caregiver would have to watch the plant almost all the time to capture momentary presence and also wondered whether pets or visitors would incorrectly indicate presence of the older adults themselves.

Some of the participants had been caregivers themselves and said that they wished they could have had video installed in the homes of their loved ones. "I wish I could have been able to keep an eye on her all the time." Other caregivers said they would have appreciated the ambient plant and being able to "see" if someone had gotten up in the morning without having to phone every day. This highlights the

possible differences, and tensions, between an older adult and a family caregiver with respect to granularity of data.

Data Transparency

Considerations of granularity also evoked discussions of data transparency. With most of our prototypes, as with most technology today, it is difficult for even an expert user to know what data is collected or communicated about activities of daily life. Participants asked many questions about how the prototypes worked. Their questions suggested a very naïve understanding of data, data collection, aggregation of data, and data sharing. For example, even after the researchers explained the MD2, participants asked very basic questions including: "Do you schedule the time almost every day? Is it one pill only? The person using it has to be alert, because it is very technical. He has to know how to turn it off." Most participants had a limited understanding of how data was collected, transmitted, stored, or shared by the prototypes.

Sensitivity of Activities

Much of the current research on technologies in the homes of older adults focuses on detecting anomalies in activities of daily living (ADLs). The presence clock (Figs. 1 and 2), the ambient plant (Fig. 3), the mirror motive (Fig. 4), and the portal monitor (Fig. 5) were designed to give subtle indications of ADLs, depending on where they were placed in the home. These prototypes also helped us explore issues of spatial privacy with participants. However, elders' discussions about these prototypes focused on the likely activities in the space rather than the space itself. Our initial framework would have suggested that there were spaces in the home, like the front door, where surveillance through the portal monitor might be acceptable. Other spaces, such as the bathroom, would be off limits. Participants instead discussed the sensitivity and/or risk of activities that would occur in the space. For example, participants liked the idea of the portal monitor as a protection against intruders or scam artists, but were opposed to having social visitors monitored. Similarly, no one wanted to be monitored while they took a shower, but many recognized the

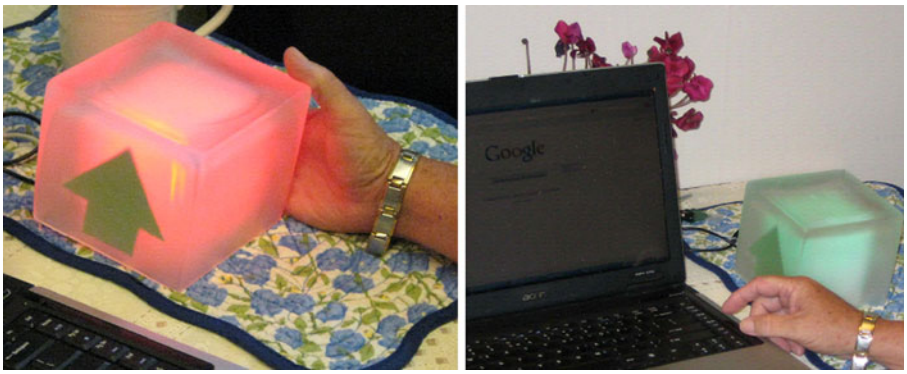

Fig. 1 Ambient Trust Cube: Cube is glowing red in left picture to indicate an untrustworthy site. It is glowing green in right figure to indicate a trusted site

Fig. 2 Presence Clock: Lights are glowing at noon—4 pm, to indicate presence in the afternoon at the paired clock

importance of some type of monitoring in the bathroom in case of a fall. The elders' acceptance of the mirror motive was predicated on what they imagined doing in the space in which it was installed. If the discussion was about being home alone, having a party, or having an intimate guest, the acceptance of the mirror motive was high, limited, or unacceptable respectively. These findings suggest the importance of flexible, activity-centric privacy designs. Older users should be able to control the flow of personal information in response to changes in activity, rather than by personally changing location to avoid/inhabit a particular space.

Discussion

The purpose of this study was to develop a privacy framework that could inform the development, adoption, and use of home-based ubiquitous technologies for older adults. We began with a five-part framework derived from the literature and tested it by asking older adults to consider a variety of prototypes. Our original framework considered privacy to be composed of the right to seclusion, autonomy, control of property (including personal data), spatial boundaries, and the ability to see verify, and correct personal data.

Fig. 3 Ambient Plant: Lights on plant pot glow in real-time when presence is detected on paired clock in other home

Fig. 4 Mirror Motive: When approached, the mirror becomes a screen and provides information about appointments, weather and medication reminders

Our results suggest that while these framings have some validity, older adults view privacy as much more contextual, individualized, and influenced by psychosocial motivations of later life. Our initial framework suggested that individualized privacy preferences would guide differences in perceptions of privacy related to home-based ubiquitous computing; some people would be highly privacy sensitive in each of the five areas while others would take a more laissez-faire approach.

While we understood that perceptions of privacy would be nuanced in later life, we intentionally began with a fairly one-dimensional framework. This framework did not sufficiently take into account theoretical perspectives from gerontology: the specific nature of aging, the choices people are willing to make, and the relational nature of privacy and autonomy. What we found was that while some participants were naturally more privacy sensitive than others, older adults balance privacy preferences against the desire for independent living, personal autonomy, and satisfying relationships. We expanded the original framework to integrate the contextual, fluid nature of privacy perception with respect to the factors articulated by our research respondents (Table 3).

The overarching themes found in the data suggest that the desire for privacy related to home-based technologies is influenced by perceived usefulness, the interactions between relationships, autonomy, and privacy, data granularity, and the sensitivity of activity (Table 3). All of these perceptions are mediated by naïve and novice mental models of data collection, sharing, aggregation, and mining. Our findings dovetail with Nissenbaum's (2004) approach to understanding privacy as *contextual integrity*, where a complex framework of individuals, institutions,

Fig. 5 Door Portal. A real-time digital photo alerts sent to a caregiver's cell phone whenever the doorbell rings or the front door is opened

Table 3 Overview of proposed privacy framework

Dimension	Relevant factors	Description
Perceived usefulness	Awareness of Perceived Vulnerability	Other, "older" people could use ubiquitous technologies; subjects did not perceive a personal need
	Critical Event Monitoring	Useful for emergencies, not daily use
Social relationships	Importance of Key Relationships	Concern about not intruding on adult children's lives
	Maintenance of Autonomy and Independence	Awareness of potential trade-off between autonomy and privacy; awareness that adult children might be making decisions for subjects; considerations of potential cognitive decline
	Data Recipient	Nature of relationships, and preferred shared data, vary among potential caregivers
	Technology Should not Replace Human Contact	Preferences and needs for human caregiving are contextual
	Reciprocal Exchange	Elders as full participants, not passive subjects, in sharing data
Data granularity	Level of Granularity	Level of acceptable granularity is highly contextual
	Data Transparency	Older adults' naïve mental models about data suggest a need to make data visible, verifiable and controllable
Sensitivity of activity	Activity vs. Space	A range of activities, with different privacy needs, can occur in any given space

technologies, laws, and policies are most useful in understanding the concept. However, our particular project suggests that theories of aging have a significant role to play in furthering our understanding of how older adults particularly respond to privacy concerns and threats.

Carstensen's Socioemotional Selectivity theory and Sixsmith's work on autonomy and independence elucidate the relevance of our proposed privacy framework for older adults. First, older adults are most interested in technologies that they perceive as useful. In general, despite evident functional disabilities, they perceive that someone else could use the technological help, but that they themselves are doing just fine as they are. Carstensen's theory posits that those who sense a shorter future are less interested in learning new things and focus instead on experiencing emotional satisfaction. The steep learning curve associated with new technologies is not worth the climb unless there is evident perceived vulnerability. Considering older adults' awareness of perceived vulnerability can give insight into the perceived useful of new technologies.

Carstensen, Sixsmith, and other late-life theorists also provide insights on the negotiation of preferred levels of support, contact, autonomy, and privacy. Many of our study participants were willing to use technologies that would help their family caregivers take care of them and stay abreast of their needs. It is very likely that perceived vulnerability may be in contrast with actual need of assistance, and family members or professional health care workers' opinions of needs of clients often conflict with the client's own self-perception of need. It is possible that data provided through the technologies could aid the parties to better understand one

another's position. Although participants expressed the desire to maintain personal autonomy, devices that are not found to be intrusive or difficult to use may be accepted by older adults in order to appease family members' concern about their well-being. Such technologies could allow the older adult to remain living as they are and provide some relief of anxiety to the caregiver or family member, thus enhancing ties between family members.

Our study found that many older adults voiced concerns about usefulness and the interactions between relationships, autonomy, and privacy, however, respondents rarely mentioned risks associated with data collection or data sharing. Similar to other research investigating older adults perceptions of privacy (Wild et al. 2008; Kwasyn et al. 2008; Courtney et al. 2008), our participants exhibited less than expected concern about privacy. "I am not worried about privacy. I am an old woman! I don't do anything to be worried about." Another noted that so far, they felt few invasions to privacy, "Well it depends upon who becomes Big Brother. Thus far, I don't think we've had too much interference with our personal life but …with all the monitoring things going on if we all of a sudden have a different form of government or different police state (it could make a difference). It's harmless information from my point of view, so I don't know how anyone else would react to it."

While participants were generally unconcerned about information privacy in this study, they were concerned about the sensitivity of certain activities being monitored. The focus on activity, rather than privacy, suggests that their mental models of information privacy may be too naïve to fully understand the risks of aggregated, shared data about activities. However, they have well-developed mental models about independence and autonomy. As Sixsmith suggests, older adults want to maintain a capacity for self-direction, free to choose what activities to do, with whom, and when, free from interference (1986, p. 341). Our findings suggest that older adults do not have a single mental model about privacy, but that their mental model is activity-centric. The variance of possible older-adult activities suggests that in-home technologies need to be easily controlled by the user.

When information privacy is not understood or managed by the older adult, there may be a danger of losing control of the data and the ability to make decisions about the collected data. Making data more transparent can help to align older adults' perceived risk with their actual risk. Privacy awareness systems (Langheinrich 2002) allow data collectors to announce and implement data usage policies and provides users with the ability to track and manage their personal information. Such systems are universally useful. Such a system would create a sense of accountability, rather than absolute security, about privacy, particularly in home-based ubiquitous computing environments.

Privacy awareness systems would benefit all of us, not just those of us over 65. For example, although a large number of Californians carry cell phones, all equipped with GPS locators, a very small number report that they regularly provide location data to authorities. We are all in need of greater data transparency. Older adults, uniquely vulnerable to infringements on information privacy, could greatly benefit from an increased awareness of how their personal information is collected, shared, and used.

Finally, late-life psychosocial theories provide broad-spectrum insights on findings, from ourselves and others, of older adults' complacency about information

privacy. Carstensen's theory about social motivation in late life (1999) suggests that coping and adaptation is enhanced by passive mastery, as well as selection and prioritization of important relationships. Passive mastery is accepting the inevitable changes of later life, but doing so with grace and dignity intact. When we ask older (70+) participants what their privacy concerns are, those who are older and have achieved some level of passive mastery are not primarily focused on immediate personal concerns such as threats to data privacy. They are focusing on internal work; contemplating the larger life questions. That is not to say they are not happy to complain about the food, the weather, or other such concerns. However, when put into a focus group, with the sense that they are contributing to an under-theorized body of knowledge, they are not likely to focus on what they might consider to be minor or trivial details related to privacy risks.

Our response to our findings was to modify the prototypes to enable user-centered transparent data control, without requiring an understanding of the operation of the prototypes or the concept of data. A selected number of modified prototypes will be deployed for 6 weeks in the homes of a small number of older adults in year three of this study. We will explore how elders' perceptions of privacy might evolve with the experience of living with the technologies.

Limitations of this study include the purposive sample composed primarily of residents of a retirement community. Their perceived need for home-based technologies could have been ameliorated by the richness of their existing emotional and instrumental social support systems. The results from this sample, chosen to be composed of likely "early adopters" with higher-than-average income and education, may not be generalizable to all older adults.

Conclusion

Our results suggest that the privacy concerns of older adults are contextual, individualized, and influenced by psychosocial motivations of later life. Our findings suggest a privacy framework relevant to home-based technologies for older adults with an interaction between perceived usefulness, the importance of social relationships, data granularity, and sensitivity of activity.

People's perceived need may be in contrast with actual need of assistance. Most participants viewed these devices as useful after a series of falls or some other demonstrated need was presented such as cognitive decline. Using technology in a preventive role was rarely mentioned. One participant suggested that sensors detecting a fall could be beneficial for a person with osteopenia who was at risk for falling, but when asked when a person might use or accept monitoring by ubiquitous sensors, most participants stated a series of falls or other demonstrated need would have to occur. If ubiquitous technology is to be used in a preventive fashion, we will need to better understand older adults' perception of prevention and self-perception of need.

Study participants expressed a need to remain in control of decisions while maintaining mutually acceptable levels of support and contact with friends and family. There is evidence that older adults do not feel as comfortable with using new technologies as younger adults. If older adults are reliant on others to manage the technological devices in their homes, it may place them at a disadvantage and may

reduce their ability to stay in control of decision-making. Vulnerability to loss of control due to naïve mental models of data privacy issues should be acknowledged and attention should be directed toward elder-sensitive design. Devices should collect as little information as is necessary, with the lowest acceptable level of granularity. The data that is collected should be visible and verifiable by the older adult. The older user should be able to easily and flexibly control what data is collected, when, and with whom it is shared.

There is hope new technologies will be developed to increase older adults' independence and ability to remain living in their homes. The development of ubiquitous technology should be directed to increase quality of life by enhancing relationships with loved ones and providing practical support for independent living. This development can be constructively informed by transdisciplinary theories of aging, which link gerontology to real-life issues (Achenbaum 2010). Our proposed privacy framework, enlightened by transdisciplinary theories of privacy and aging, can inform the development of home-based ubiquitous technologies that contribute to optimal aging in a dynamic society.

Acknowledgments This material is based upon work supported by the National Science Foundation under award number 0705676. Any opinions, findings, and conclusions or recommendations expressed in this presentation are those of the author(s) and do not necessarily reflect the views of the National Science Foundation.

Conflict of Interest Notification Page There are no potential conflicts of interest that might bias this work.
None of the authors have financial or personal relationships that might influence the findings in this study.
No other individuals besides the authors provided writing assistance.
All of the authors completed a Conflict of Interest disclosure statement, in accordance with IRB protocols, for this study.

References

Achenbaum, A. (2010). 2008 Kent award lecture: an historian interprets the future of gerontology. *The Gerontologist, 50*(2), 142–148. doi:10.1093/geront/gnp142.

Beach, S., Schulz, R., De Bruine W., Downs J., Musa D., & Matthews J. (2008). Privacy attitudes and quality of life technology in disabled and non-disabled baby boomers and older adults. Presented at the 2008 Gerontological Society of America (GSA 2008). Washington, DC.

Bloustein, E. (1968). Privacy as an aspect of human dignity: an answer to Dean Prosser. *New York University Law Review, 39*, 962–970.

Boyle, M. (2003). A shared vocabulary for privacy. Presented at the 4th International Conference on Ubiquitous Computing. (UbiComp 2002), Berkeley, CA.

Cantor, M. (2006). No information about me without me: technology, privacy, and home monitoring. *Generations, 30*(2), 49–53.

Carstensen, L., Isaacowitz, D., & Charles, S. (1999). Taking time seriously: a theory of socioemotional selectivity. *American Psychologist, 54*(3), 165–181.

Centers for Disease Control and Prevention (CDC). (2010). National Center for Chronic Disease Prevention and Health Promotion. Available via the Centers for Disease Control. http://www.cdc.gov/brfss. Cited 16 August 2010.

Courtney, K., Demeris, G., Rantz, M., & Skubic, M. (2008). Needing smart home technologies: the perspectives of older adults in continuing care retirement communities. *Informatics in Primary Care, 16*, 195–201.

Czaja, S., Fisk, D., Hertzog, C., Rogers, W., Charness, N., Nair, S., et al. (2006). Factors predicting the use of technology: findings from the Center for Research and Education on Aging and Technology Enhancement (CREATE). *Psychology and Aging, 21*(2), 333–352.

Davis, F. (1989). Perceived usefulness, perceived ease of use, and user acceptance of information technology. *MIS Quart, 13*, 319–339.
Geraci, J. (2004). Community and boundary in the age of mobile computing. Presented at the Workshop on Ubicomp in the Urban Frontier (UbiComp 2004), Nottingham, UK.
Introna, L. (2003). Privacy and the computer: why we need privacy in the information society. *Metaphilosophy, 28*, 259–275.
Jiang, X. (2002). Safeguard privacy in ubiquitous computing with decentralized information spaces. Presented at the 4th International Conference on Ubiquitous Computing (Ubicomp 2002), Gotenborg, Sweden.
Keyes, C. (2002). The exchange of emotional support with age and its relationship with emotional well-being by age. *Journals of Gerontology: Psychological Sciences, 57B*, 518–525.
Kwasyn, M., Caine, K., Rogers, W., & Fisk, A. (2008). Privacy and technology: Folk definitions and perspectives. Proceedings from CHI 2008, April, 2008. Florence, Italy.
Langheinrich, M. (2002). Privacy invasions in ubiquitous computing. Presented at the 4th International Conference on Ubiquitous Computing (UbiComp 2002), Gotenborg, Sweden.
Melenhorst, A., Rogers, W., & Bouwhis, D. (2006). Older adults' motivated choice for technological innovation: evidence for benefit-driven selectivity. *Psychology and aging, 21*(1), 190–195.
Mell, P. (1996). Seeking shade in a land of perpetual sunlight: privacy as property in the electronic wilderness. *Berkeley Technology Law Journal, 11*, 1–92.
Miles, M. & Huberman, A. M. (1994). *Qualitative data analysis: An expanded sourcebook* (2nd Edition). Thousand Oaks, CA: Sage.
Nissenbaum, H. (2004). Privacy as contextual integrity. *Washington Law Review, 79*(1), 101–158.
Odlyzko, A. (2004). Privacy, economics, and price discrimination on the Internet. In L. J. Camp & S. Lewis (Eds.), *Economics of information security* (pp. 187–213). Waltham: Kluwer.
Sixsmith, A. (1986). Independence and home in later life. In C. Phillipson, M. Bernard, & P. Strang (Eds.), *Dependency and interdependence in old age: Theoretical perspectives and policy alternatives*. London: Croom Helm.
Tomita, M., Mann, W., Stanton, K., Tomita, A., & Sundar, V. (2007). Use of currently available smart home technology by frail elders. *Topics in Geriatric Rehabilitation, 23*(1), 24–34.
van Bronswijk, J., Bouwhuis, D., Fozard, J., & Bouma, H. (2008). Gerontechnology's basics. *Gerontechnology, 7*(2), 80.
Warren, S., & Brandeis, L. (1890). The right to privacy. *Harvard Law Review, 4*, 193–220.
Westin A. (2001). Opinion surveys: What consumers have to say about information privacy. Prepared Witness Testimony, The House Committee on Energy and Commerce.
Wild, K., Boise, L., Lundell, J., & Foucek, A. (2008). Unobtrusive in-home monitoring of cognitive and physical health: reactions and perceptions of older adults. *Journal of Applied Gerontology, 27*, 181–202.

Lesa Lorenzen-Huber is a Clinical Assistant Professor in the Applied Health Science Department, School of Health, Education, and Physical Recreation (HPER), at Indiana University-Bloomington. Her research interests include gerontology and geriatric education for health care professionals, physical activity and aging, creativity and aging, gerotechnology, and pedagogical strategies in distributed education. She received her Ph.D. in gerontology from the University of Lincoln-Nebraska. She can be reached at lehuber@indiana.edu or Smith Research Center, Room 197, Bloomington, IN 47405.

Mary Boutain completed her Masters degree in public health at Indiana University and works at Area 10 Agency on Aging in Ellettsville, Indiana.

L. Jean Camp is an Associate Professor at the School of Informatics and Computing, Indiana University-Bloomington. Her research focuses on the intersection of social, economic and technical trust. She received her doctorate from Carnegie Mellon University in Engineering and Public Policy. She can be reached at ljcamp@indiana.edu or 901 E 10th Street, Rm 200, Bloomington IN 474703.

Kalpana Shankar is an Assistant Professor at the School of Informatics and Computing, Indiana University-Bloomington. Her research interests include scientific recordkeeping and data management practice the uses of pervasive computing in shaping social relationships. She received her Ph.D. in library and information science from the University of California, Los Angeles. She can be reached at shankark@indiana.edu or 901 E 10th Street, Rm 303, Bloomington IN 474703.

Kay Connelly is an Associate Professor in the School of Informatics and Computing at Indiana University-Bloomington. She is the Senior Associate Director of IU's Center for Applied Cybersecurity Research. Her research focuses on user acceptance of ubiquitous and mobile computing and health and wellness applications to empower both the ill and the healthy to manage and improve their own health and make healthy choices. She received her Ph.D. in computer science from the University of Illinois, Urbana-Champaign. She can be reached at Connelly@cs.indiana.edu or Lindley Hall 301D, 150 S. Woodlawn Ave, Bloomington, IN 47405.