Privacy, pervasive computing, and the elderly: Methodological challenges

Kalpana Shankar

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Abstract

Introduction Although a number of projects and studies have examined the usability of home-based ubiquitous computing and design for aging, there has been little integration of privacy and ethical concerns into this discourse. This paper describes some of the methodological challenges of investigating privacy and ubiquitous computing in the home, particularly among the healthy elderly.

Method Based upon extensive review of the privacy and aging literatures, prototypes of home-based ubiquitous computing devices were created and deployed in a home-like Living Lab setting; elders were brought to the Lab to interact with the prototypes, then brought together in focus groups to discuss their insights and concerns.

Analysis/Findings Transcripts of discussions with elders and larger focus groups were open coded for themes relating to privacy, usability of prototypes, and other concerns. Methodological challenges of data transparency and meaning, utility of prototypes, and communication between researchers and elders regarding privacy are discussed.

Conclusion Considerations for future studies of the elderly and privacy are explored and iterations of method and prototype development discussed.

Introduction

The integration of computational tools into everything from our cars and factories to our milk cartons and clothing promises mobile, embedded, universally accessible information technologies for one and all – the next generation of computing. One area in which mobile and pervasive computing (also called ubiquitous computing, or ubicomp) is touted as gracefully integrating the human and the computer is in home-based computing for aging in place. There is a great deal of research and development on pervasive technologies that simplify the performance of activities of daily living, monitor health, enhance social connectedness, and allow distant caregivers and elders to participate in each others' lives (Demiris et al 2008).

The hope for ubicomp and mobile technology is that environmentally embedded devices can provide a way to assist elders and their caregivers in several ways; coordinating communications among a network of caregivers (Consolvo et al 2004), provide caregivers feedback on the elder's activities, and inform them of acute situations that may need immediate intervention. These technologies can also allow patients to monitor their own health conditions more readily. Some examples of these technologies range from Personal Digital Assistants (PDAs) for dialysis patients to monitor their food intake (Connelly et al 2005) to Oatfield Estates, an entire adult assisted-living facility with embedded networked technology in Oregon designed to support active living. Such technical interventions may allow greater

autonomy for the elderly, who may be able to age in place in their own homes if their caregivers can easily monitor them. However, the use of these pervasive devices can go well beyond health maintenance to enhance well-being by providing social connectedness, a safe physical environment, and enhancement of daily activities.

Not surprisingly, these pervasive technologies engender a number of challenges and concerns. How can designers of such technologies embed privacy considerations in the design and deployment of such technologies? How is privacy understood in this context? What constitutes ethical research and development for a population that may be given little choice in the adoption of these technologies? How can designers and design students, elders, and caregivers be educated about privacy and home-based computing? In this paper, I describe a larger project on technology, privacy, and ageing, then address some methodological concerns and our approaches to overcoming them.

Review of the Literature

The aging of the world's population and rising health care costs represents a confluence of trends that is precipitating a crisis. Not surprisingly, insurance companies, legislators, and others with a vested interest in reducing the cost of home health care and reducing the number of individuals in nursing home settings are pushing for technological solutions (or at the very least, assistance) to making home-based health care more affordable and approachable. However, health care is not the only consideration. . As the Baby Boomer generation retires - the largest, most well educated retiring population in history (Walker & Sarfatti 2007) – they are increasingly interested in remaining in their own homes for as long as possible. This requires technology that does more than monitor; it suggests that technology can and should also be used to promote active aging.

Demographic changes are in this case accompanied by new technological possibilities. Decrease in processor size, users' comfort and familiarity with mobile devices, and the relative ease of creating applications for mobile devices such as cell phones makes ubiquitous computing more in the reach of all demographics. Researchers and commercial concerns have been catering to these trends by developing technologies that can be used to keep people in touch with family and friends, provide reminders, enhance safety and well-being, and monitor daily activities, not just for the elderly, but for others as well (Kimel and Lundell 2007; Mynatt and Rogers 2002).

Unfortunately, current trends in pervasive design have done little to enhance their privacy enhancing reputation. This is particularly evident when technologies for eldercare are created; privacy and autonomy are presented as competing choices, with autonomy winning. There is some disagreement about this in the literature, though. While some studies have found that elders and their caregivers will settle for abdication of their privacy concerns when presented with options that may be less than palatable (Mynatt et al 2004), others have found that privacy concerns are

not always superseded by concerns for physical safety and health (Caine et al 2008). Gerdes (2007) argues that elder care has become increasingly one in which a "surveillance culture" operates, particularly in institutional settings; home-based ubicomp has the potential to exacerbate this cultural shift. Vuokko (2008) expands upon this premise to suggest in spite of the potential for modernizing service delivery to senior citizens, the surveillance potential of mobile technologies shifts power dynamics and marginalizes the elderly users of technology, even in their own homes. To date, not enough research has been done on articulating and operationalizing privacy for this demographic of end users, much less creating devices that are sensitive to the privacy needs and concerns of older adults (Hilty, Som, & Kohler 2004).

Operationalizing privacy as a design constraint is complex and requires appropriate integration into the design of new technology. The definitions of privacy in a technological context are multitudinous and often in conflict with each other (Kwasny et al 2008). Camp and Connelly (2007) argue that the most prevalent framing of privacy enhancement insufficient for pervasive computing, particularly in the context of health care. For example, if one accepts the premise that boundaries of various kinds (spatial, relational, etc) are sufficient for privacy protection, where should the boundary be drawn in the "network" encompassing an elder's home and the mobile monitoring device used by his or her caregiver? The transmission of an elder's medical and activity data between and across wirelessly connected devices blur physical boundaries and introduce problems of data ownership, data mining, and security of devices.

A data protection approach, based on transparency, consent, and correction (Camp & Connelly 2007) is similarly insufficient. The quantity of streaming data generated by monitoring technologies is likely to be difficult to manage and present to a patient for a number of reasons, cognitive and otherwise. The notion of "correction" of personal medical information is similarly difficult. Data protection embeds transactional expectations, with each transaction having appropriate framing and consent. But pervasive technology is built not upon events but rather continuous flows of micro-data. How one consents, and what one consents to in a pervasive computational environment is problematic. For example, consider just two of an aging elder's potential options: aging in one's own home with monitoring technologies installed or going to a nursing home or similar facility. The former, if the technologies are not designed with appropriate controls and transparency of data collection, may not permit the elder to fully understand what s/he is consenting to with respect to data collection and use or on/off mechanisms (for example, some commercial monitoring technologies cannot be turned off or controlled in any way once installed). In the latter case, surveillance may or may not be technologically mediated, but similar issues regarding monitoring and control may be present.privacy should require not just understanding of the particular sensor or network, but how the data is going to be used. Consent must be given to various uses of the data and its presentation – a complicated task. This conundrum suggests another important framing of privacy: as a form of data protection. If end-

users will be expected to interact with and make decisions based on data collected in ubicomp environments, appropriate measures must be in place to make that sensitive data understood by the layperson, protected, and preserved (Strickland and Hunt 2004). Grappling with the challenge of making data available to and accessible by multiple communities with different levels of expertise is an ongoing subject of research in digital libraries and other closed repositories, but pervasive and mobile medical technologies increase the stakes well beyond the user communities that most in the information studies communities are equipped to handle. However, as with other technologies, these kinds of devices become obdurate, resistant to post-hoc modification and reuse. In other words, privacy (or other ethical considerations) cannot be treated as add-ons or applied after design and deployment.

To counter this form of technological determinism and counteract inherent biases, Friedman and Nissenbaum (1996) posit that values built into a new technology from the outset stand a better chance of being grounded in the concerns of the user population if it is done explicitly (Friedman, Kahn, and Borning 2006). A strong, nuanced understanding of the phenomena of interest – in this particular case, privacy and technology – is necessarily built upon empirical data and requires conducting research with the affected population in a context that acknowledges the complex of factors that influences design adoption. Building upon an explicit statement of the principles and values upon which a particular device will be built is, in turn, built upon appropriate conceptual and theoretical investigations. Taking this approach to information technology would argue for a nuanced understanding of what privacy means to the user community which is being affected (in this case, elders) and explicitly building this into the design of home-based ubicomp.

However, it is difficult to predict beforehand when privacy will be important, which conceptualizations will strike closest to home, and which devices will elicit the most concerns and questions. Furthermore, privacy considerations will be nuanced by other concerns – security of a system, usability, and interactions with other devices. Integrating individual preferences, social situation, and context into a privacy framework for design, what Shilton et al call "participatory privacy" (Shilton 2008) requires multiple methodological interventions such that researchers think carefully about both the population and the context of design and development of new technologies. While there has been some research on these issues (Mynatt et al 2004), lack of real-world deployment of devices and explicit focus on privacy has hampered greater understanding of how to make ubicomp privacy-sensitive. While there has been extensive research and development in the arena of privacy-sensitive technologies in general, little has been applied to home-based ubicomp and the elderly. Yet research has shown that individuals' personal and social contexts and physical environment contribute highly to their notions of privacy.

Research Design

We began with our goal of developing a robust privacy framework that accurately reflects the privacy and security concerns of our target demographic group. Our

intention was to create framework could be operationalized in a toolkit for designers interested in creating privacy-sensitive ubicomp devices and a separate set of tools for end users to manage these devices at their end. Three separate but important considerations influenced our research design: focus on the elderly, a demographic traditionally underserved by design and privacy communities; a privacy framework for home-based ubicomp; concrete design explorations of home-based technologies.

Our first goal was to begin to understand some of the privacy concerns of the group for whom we are designing; thus, we began with considerations of sample selection. This area of research has presented us with numerous methodological challenges. The wide range of experiences and preferences of this or any demographic has also made consistent sampling difficult (Mayhorn, Fisk, and Whittle 2002). The specific age range, cognitive and physical abilities and states, educational level, socioeconomic status, and familiarity with information technology are at least some of the markers that differentiate this large demographic, and it is almost impossible to incorporate all of them into a singular design framework. However, prior research suggests that many physical and cognitive declines accelerate after the age of 75 (Nichols, Rogers, and Fisk 2003). Our own research suggested that individuals under the age of 65 were in many cases still caring for elderly family members and often spoke as informal caregivers and not as potential users of home-based ubicomp. Building on prior research with seniors and their privacy perspectives (Kwasny et al 2008; Caine et al 2007) we began with a conceptual framework of privacy operationalized in prototype home-based ubicomp designs (described in detail below), tested their utility and validity with at least a sample of the population to rule out (or rule in) specific concerns, and triangulate those findings with others from the literature. We began by focusing on healthy elders of minimum age sixty five.

A second piece of the research design that we considered to be essential was the design of prototypes and the space in which artifacts could be demonstrated and discussed. The literature (and possibly common sense) suggests that individuals will have much more engagement with home-based ubicomp if they could envision the kinds of devices that could potentially be of use in their homes in a natural setting (Mynatt et al 2004; Consolvo & Towle 2005). To this end, we constructed a "Living Lab", a renovated one bedroom apartment for conducting research, deploying design prototypes and off-the-shelf devices, and conducting tours. The prototypes were built to illustrate both the privacy framings (or metaphors) and to reflect what the literature has suggested are important kinds of activities part of the daily lives of elders: activities of daily living, health monitoring and management, social connectedness, and physical safety. We also augmented our array of prototypes with commercial software and devices that illustrated the privacy and activities described. Devices included a front door monitoring system that is triggered by the doorbell ringing; a "brain age" computer game; a stress-level monitoring game; a wall-mounted mirror that could store and transmit information; a medication dispenser that could call a caregiver if medication was not taken; and a

pair of plants with motion sensors that are triggered by motion near the other plant to convey a gentle sense of presence.

	Activities of daily living	**Health monitoring**	**Physical safety**	**Social connectedness**
Data protection	Mirror	Brain game Stress monitor Medication dispenser		
Autonomy			Door monitor	Mirror
Seclusion	Mirror	Medication dispenser	Door monitor	Plant
Spatial boundaries	Plant		Door monitor	
Data as property	Mirror	Medication dispenser	Door monitor	

To test our prototypes in situ and assure the robustness of our research design, we ran preliminary focus groups, one with six participants and one with ten. All were recruited informally. Each group consisted of healthy elders living independently. Although we did not select for these characteristics, each group consisted of members between the ages of sixty-five and eighty, both men and women. Most were married, but we also had several single individuals. All had high levels of education and were familiar with using various forms of information and technology and mobile devices.

Each focus group was conducted at the Living Lab. Respondents were debriefed, given study information sheets and time to ask questions about them, then given a brief questionnaire with questions about their familiarity with home-based technology, computing, and demographic information. Respondents met with one researcher in different rooms around the house for approximately ten minutes to examine the prototypes and share their impressions; each session was videotaped and audiotaped. The researchers developed open-ended scripts that described the prototype or commercial device, elicited responses regarding the usability and design of the device, and asked the respondents to reflect on privacy and security concerns without explicitly focusing on those ideas.

At the end of the interactive session, all of the researchers and elders were brought together in a focus group setting of approximately one hour. One researcher introduced scenarios that illustrated each of the five privacy metaphors elicited from the literature: seclusion ("the right to be left alone"), personal autonomy, spatial/boundary-related privacy, data as property, and data protection. These scenarios did not specifically reference the prototypes that the respondents saw, although they were discussed by many of the respondents. We concluded with open-ended questions and discussion that allowed the elders to discuss their other concerns, suggestions for improvement of the prototypes, and ask questions of the researchers.

Based on these pilot studies, we modified the designs of the prototypes as necessary, refined the scenarios for the focus groups, then conducted similar studies with the same prototypes with forty-five seniors living in a retirement community. These seniors were also living independently but at a continuous care retirement facility. In age range, level of education, and other characteristics, these individuals were very similar to our initial pre-test group.

Perhaps most importantly, we endeavored to ask about privacy without explicitly asking about privacy. While asking questions about data sharing, the private spaces in the home, and tasks that engendered privacy concerns would have been straightforward, we strove to find more indirect mechanisms for eliciting answers. Our concern was that our own biases regarding what we considered private, what we considered public, and what was ambiguous would influence our framework too heavily. Instead, we wished to elicit those of our respondents and in their own words.

In the next sections, we focus specifically on the methodology with which we approached our task. We concentrate on three areas of interaction illuminated by our methods: elders' interactions with the devices and prototypes, interactions with the notion of data, and affective considerations.

Discussion

Interactions with Prototypes

We chose to use both commercial devices and experimental prototypes to engage conversation and present the respondents with concrete objects with which to engage. For the initial two focus groups, we developed an "Ambient Plant", which allowed elders to care for a plant in their home while another person did the same. However, the plants were networked with each other through computers and sensors that indicated dryness of soil (i.e., neglect of plant), proximity of other individual to his/her respective plant. A second prototype, the "Mirror Motive", consisted of a wall-mounted mirror that responded to motion and displayed messages, video feed, and received binary input through the motion sensor (Rege et al 2008). A third was an event-driven portal monitor that would send photos of people at the door to a cell phone or email address. Commercial devices included an

automated programmable medication dispenser with a built-in phone line that could alert an individual or service if a particular medication was not taken on time; a biofeedback game for monitoring and reducing stress; and a computer-based card game that measured cognitive reaction times. The researchers endeavored to create prototypes and use commercial technologies that engendered conversations around privacy by deliberately selecting or creating devices that stored or transmitted information about the elder or others.

The introduction of working prototypes and commercial devices in the context of a home (and not a laboratory) proved successful on several levels, but not necessarily on elucidating concerns of privacy. For one, seeing the prototypes in a home-like setting and not in a laboratory allowed research participants to envision how such objects might work in their own homes. Although all of the devices provided tangible discussion points for researchers and elders, they presented several difficulties. The first was that it became very difficult to illustrate the different privacy frameworks with the devices that had been chosen or developed. While data protection was straightforward to illustrate, the other metaphors were less so, at least with the devices that we had created. The second issue concerned the look and feel, or form factor, of the devices. Several of the devices were large, awkward, or physically somewhat unattractive. Respondents tended to focus on the look and placement of the object and not on its functionality, and even less on the privacy concerns that the artifact might present. The last issue that arose, ironically, was about setting and context. We had anticipated that having objects in a home-like setting would be the most natural launching point for discussion. While this proved to be somewhat the case, the objects themselves were disconnected from each other and did not lend themselves to working with each other, or with the particular rooms in which they were displayed. For example, the layout of the Living Lab, constructed in a house built in the 1920s, precluded us from putting the mirror (50" in diameter) in another room other than the living/sitting room. The respondents found this an odd choice, and commented on the location. Also, since the devices were not connected to each other, they seemed somewhat capriciously chosen. This prevented our respondents from considering the objects as part of a whole where new technologies would integrate with the existing infrastructure of the home. Thus, questions often arose around whether the mirror would work with the stress meter or the medication dispenser (for example). Several of the devices were not home-based ubicomp at all (for example, the stress game) but were more explicitly targeted to eliciting conversations about medical monitoring and data protection. Lastly, it became clear that a key area of daily living, financial management, had not been included in our suite of devices.

We are taking steps to address some of these considerations while acknowledging that some may not be easily addressable. The house setting itself is being remodeled and renovated to allow us to integrate the prototypes more thoroughly and more seamlessly into a natural setting. We are also attempting to address some of the concerns raised in the pre-test focus groups in the interview tools. For example, we are careful to emphasize in our scripts that the devices are merely

examples of the kinds of technologies currently in development and in the market, and thus should be considered separately from each other and should be considered works in progress. We are also planning more focused and more extensive usability testing with the experimental prototypes, differentiating the home-based ubicomp devices from those that are more related to measurement and assessment of various faculties. The latter proved to be important to maintaining a diversity of tasks and features in the new technologies. Our own technology development focus will be on creating new prototypes that fulfill our multiple demands: presenting elders with a variety of home-based functions for enhancing their quality of life, challenging at least one of the privacy frameworks that we are testing, and presenting more attractive physical forms that fit more gracefully into their natural setting.

Understanding "Data"

The concept of privacy as data protection has been one of the most difficult to conceptualize and to convey. The prototypes and the commercial devices have been designed if not to actually collect live information to at least give the appearance of being able to do. Kinds of information collected included health and stress monitoring, cognitive ability, movement, location, daily patterns of activities, and preferences (for example, whether the elder was interested in attending an event or outing). The questions around each device pertained to data protection and the ability to verify, correct, share, and delete data that had been collected about them, and give permission for collection, reuse and matching against other kinds of databases.

However, there have been several problems with the concept of data. The first is that the very idea of "personal data" has proven to be too abstract to elicit responses, although once examples were provided and discussed, respondents could envision the kind of information being collected (and potentially distributed or reused in other ways). Although the respondents were familiar with the kind of financial and personal information that related to "phishing" or other Internet-based scams, they had trouble envisioning other kinds of personal information that might be collected or why anyone would want to gather such information about their daily whereabouts, whether or not they had taken their medication, and their stress levels. They were equally mystified when asked about whether they would voluntarily share this information and with whom, since this question related to why others might want this information.

These disconnects between the researcher's framing of "personal data" (and the relative importance s/he places on its relationship to privacy) and the respondents' conceptualization illustrate some of the difficulties of making data a concrete artifact around which discussion can be had. Creating a visual representation of "collected" data and ways in which it could be used, manipulated, deleted, or mined is one approach that might be effective in eliciting more concrete comments and suggestions. However, concerns arise here as well. Collecting real data on participants might not be feasible with all prototypes or commercial devices; interestingly, the data trail gathered by commercial devices is usually not made

accessible to the end-user. Using a Wizard of Oz protocol to display data as it if had been collected has some advantages and drawbacks. While using a visual representation of such data can convey more immediately the kind of data that is collected about individuals by home-based computing applications, if the data is troubling or private, respondents might become alarmed or concerned for no reason. Another approach is to share "data" that has been collected or mocked up about a third individual, a researcher or an unknown person. This has the advantage of sharing a visual representation, but it is unclear how that will elicit discussion.

Even if it is agreed that "showing data" is the most useful approach, how this data (real or mocked up) is presented to the end user may further influence how the respondents react to the data collection aspects of the prototypes and devices. For example, if daily stress levels are presented to the end-user, it is not clear if the concept of "data" will be made more clear if it is presented as a graph, a spreadsheet, a list of numbers, or in some other format. Understanding the interaction of data and user where the user is not intrinsically "data driven" is an open research problem with large ramifications.

Affective Considerations

The third piece of the methodological puzzle is perhaps more familiar to researchers who are studying sensitive subjects, but proved to be of import in this study. Researchers in the social science disciplines have noted that it can be difficult for participants in a study to personalize their experience, or convey their true beliefs to the researcher, particularly if the subject is potentially a sensitive one. In this studies described above, the researchers had some difficulty in eliciting the respondents beliefs regarding home-based computing and the need for privacy. In many cases, the respondents would externalize their beliefs by saying, "I have no need for such a device, nor would I use one, but my 95 year old grandmother should have one." In other discussions, respondents would suggest that their more elderly neighbor or relative should be monitored constantly, but when the researchers attempted to personalize the conversation to ask how the respondents would feel about such an approach to technology in their own lives, they met resistance.

This is not a surprising turn of events, but it does suggest a need for more nuanced ways of eliciting concerns about autonomy and privacy. Since the population we are studying is generally healthy, living in their own homes, mobile, educated, and high-functioning, it is not surprising that they had difficultly imagining their own need for the kinds of devices we were presenting. It also stands to reason that the most "monitoring" devices (with clear implications for privacy and security) received the most discussion around them rather than the social networking applications. Many of the respondents were in the position of caring for elderly relatives themselves, or had recently done, and perhaps appreciated the kinds of monitoring afforded by the prototypes we presented. This generation is not as familiar with the use of computing devices to create and maintain online social networks, so those technologies (and their privacy implications) seemed of less interest (although

social networking was the initial intent of many of the student designers who initially suggested the prototypes). Perhaps most important of all, there is a natural disinclination to engage with the kinds of conversations these prototypes engendered because they were predicated upon declines in autonomy, the individual ability to make decisions, and the agonizing Cornelian dilemma of relinquishing privacy for the ability to live independently for a longer period of time. Furthermore, we found a general agreeableness in our participants that made it difficult to get at the "general good" of elders. We need to consider refinements to our protocol that acknowledge this problem. We plan to do more key informant studies and are considering ways in which our on-site focus groups could elicit more information.

Working with this population also requires understanding of personal dynamics that may characterize it. Responses to the prototypes and devices often varied by gender, whether or not the individual was partnered (and thus perceived less need for some of the technologies), and age-cohort. A respondent from a local assisted living facility perceived her own needs for both socialization and monitoring differently than those who lived in their own homes.

Conclusion

As we acknowledge, numerous framings of privacy are possible. We selected a subset of these, implemented them in prototype designs that might be of potential use and interest to elders, and used them to discuss how the kinds of data they collected and potentially distributed might affect technology adoption and considerations of privacy in home-based ubicomp. The different kinds of artifacts and devices that we used in our studies created a more comprehensive information ecology (Nardi 1999) than we had anticipated – one that integrated physical space, social networks, and other appliances and devices in the home. Since we had little control over this complex set of relationships, we encountered difficulties in disambiguating the relationship with and reactions of our participants to our prototypes from other human-human and human-technological relationships, topics that will be explored in subsequent papers.

Although this paper might suggest that our initial project "failed", for reasons we outline in this paper, we took several lessons that we have since iterated upon in follow-up studies. Since the data is still being analyzed, this paper will only touch on our methodological interventions, the focus of the current paper.

Our first intervention was to make the use of prototypes and their data collection and use clearer. To do this, we created video "skits" in which we asked actors and a narrator to describe the technology, show its use in the home of an elderly person, and describe the kind of data collected. We have also augmented one of the prototypes, the Ambient Plant, to make it more in tune with what elders seemed to want: a safety and physical monitoring device. To do this, we created a Presence Clock, which implemented similar motion sensors to indicate presence, but enhanced with lights that would indicate when a person had been near the lock,

creating a "history". We have also begun conducting more interviews and focus groups with senior citizens who are not living in a structured community setting. Initial results show differences from our earlier studies, both in understanding of the technologies (and their personalization) and the perceived utility of our designs.

For others conducting research on similar topics, our experiences would suggest that creating a research design that simultaneously provides replicable, useful results and honors and respects the individuals that constitute the population under study is a balancing act. This can made even more complicated when the kinds of phenomena under study constitute potentially personal or sensitive ones.

By definition, a user-centered approach to designing and evaluating information systems suggests that the designer should engage with the end-user community to understand its needs and include them in both the design criteria and evaluation process. But as this project suggests, understanding the user's perspective is problematic if the concept is as contested as the word "privacy". This issue is of increasing concern to researchers in embedded systems (Shilton 2008), but should be targeted more explicitly to the aging population. Although design for non-traditional environments is difficult as their operational constraints are difficult to control and predict (Bennett et al 2006), basic principles of good design for an aging populace do exist. What is still needed is more emphasis on the values inherent in those designs – privacy being only one of them.

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