Breathing Room in Monitored Space: The Impact of Passive Monitoring Technology on Privacy in Independent Living

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Abstract

Purpose of the Study: This study examines articulations of the relationship between privacy and passive monitoring by users and former users of a sensor-based remote monitoring system. A new conceptualization of privacy provides a framework for a constructive analysis of the study’s findings with practical implications.

Design and Methods: Forty-nine in-depth semistructured interviews were conducted with elder residents, family members, and staff of 6 low-income independent living residence apartment buildings where the passive monitoring system had been offered for 6 years. Transcribed interviews were coded into the Dedoose software service and were analyzed using methods of grounded theory.

Results: Five diverse articulations of the relationship between privacy and passive monitoring emerged. The system produced new knowledge about residents and enabled staff to decide how much of that knowledge to disclose to residents. They chose not to disclose to residents their reason for following up on system-generated alerts for 2 reasons: concern that feelings of privacy invasion may arise and cause dissatisfaction with the technology, and the knowledge that many resident users did not comprehend the extent of its features and would be alarmed.

Implications: This research reveals the importance and challenges of obtaining informed consent. It identifies where boundary intrusion can occur in the use of passive monitoring as well as how changes to technology design and practice could create opportunities for residents to manage their own boundaries according to their privacy needs. The diversity of approaches to privacy supports the need for “opportunity for boundary management” to be employed as both a design and practice principle.

Keywords: Privacy, Activity monitoring, Passive monitoring, Sensors, Long-term care

The technological generational shift from active personal emergency response systems (PERS) to passive continuous monitoring installed in the living space of older adults has raised concerns about the invasion of privacy (EFORTT, 2011; Lorenzen-Huber, Boutain, Camp, Shankar, & Connelly 2011; Shankar, 2010). It also raises the question of how we understand privacy in today’s context where ubiquitous trackability, digitized selves, data mining, big data, and predictive analytics proliferate. How do we ask questions about new socio-technical care practices that appear to challenge existing expectations and meanings of privacy? Moreover, what are our understandings of what purposes privacy serves and how do these understandings guide us to develop policies and practices to protect it?

Innovation that accommodates the privacy needs of older adults is constrained by the slow-to-evolve ways in which we conceptualize privacy, its role, and significance. Most of the literature in which privacy and personal health monitoring are discussed focuses on “information privacy”, that is, aspects related to one’s own control and dissemination...
of personal data (Mittelstadt, Fairweather, McBride, & Shaw, 2013). Personal privacy—unenable to data security enhancement solutions—receives scant treatment and is often framed as a hurdle to acceptance rather than a normative concept (Mittelstadt et al., 2013). In this article, I present research on a sensor-based monitoring system that had been used by an early-adopter independent living organization for 6 years. This analysis supports and is further illuminated by a new conceptualization of privacy for a digital age.

The majority of the research on home monitoring technology for older adults names both a tension and a trade-off between values of privacy and autonomy or safety, whereas others describe it in more dynamic terms of striking a balance. In a review of the literature, Townsend, Knoefel, and Goubran (2011) conclude that older adults will trade privacy for autonomy. The idea that continuous home monitoring can be perceived as protecting one’s privacy has been raised in multiple studies, in terms of trading some privacy loss for greater privacy loss in alternative residential settings (Essén, 2008; Lorenzen-Huber et al., 2011; McLean, 2011). Researchers have also highlighted the subjective nature and diversity of experiences of privacy with passive monitoring, as well as differences between older adults and family members with regard to perception of need and comfort with various levels of data granularity (Hensel, Demiris, & Courtney, 2006; Lorenzen-Huber et al., 2011). In one study, older adults reported that their perception of need would supersede any privacy concerns, but they did not think that they personally would need passive monitoring technology despite their current advanced chronic conditions (Courtney, Demiris, Rantz, & Skubic, 2008).

Knowledge of monitoring data collection and sharing is required for one to reflect on how it protects or violates one’s privacy, yet studies indicate that older adults have difficulty in understanding what data are collected and how they are accessed. Based on design research with working-age adults, Bellotti and Sellen (1993) found that the principles of control and feedback were integral to privacy solutions. They recommend asking eight questions of a product regarding whether users have control over and receive feedback about what information is collected and when, what happens to the information, which people have access and what do they see, and why people want the information (Bellotti & Sellen, 1993). If considered, these principles are not met in remote monitoring product design for older adults. In a study of privacy and information technology, older adult focus group participants had “naïve mental models” about information privacy, difficulty in understanding what data were; why they would be collected; and how they would be stored, shared, and accessed (Lorenzen-Huber et al., 2011; Shankar, 2010). This finding highlights a potential bioethical issue of obtaining informed consent that is actually informed.

Extant research on passive monitoring’s impact on older adults’ privacy has not thoroughly drawn out articulations of privacy (Shankar, 2010). The identified disconnect between privacy theory and applied research and product development (Mittelstadt et al., 2013) is significant because it may prevent the development of technologies and associated care practices that meet the privacy needs and preferences of older adults.

### The Meaning of Privacy Today: Opportunity for Boundary Management

One of the reasons scholars perceive continuous passive monitoring as a potential threat to privacy is because privacy has largely been defined in relation to space. Within a legal framework, the home has been thought to be a private space in relation to public space where consent to be observed is assumed upon entering it (Cohen, 2012; EFORTT, 2011). The line is blurred between public space and private home space with the collection of behavioral biomarkers in one’s home. The use of these technologies in one’s personal home space results in a “different psychological dynamic” than that operating in an institutional setting (Hensel et al., 2006, p. 430).

The breakdown of the public/home space divide, as well as shifting norms about what information should be private, does not necessarily indicate a parallel erosion of expectations for privacy. It is important to remember that technology evolves along with norms and ways of interacting with technology. Privacy—like risk management—is an evolving value. In the literature on passive monitoring, authors commonly frame it as a trade-off: privacy versus autonomy/independence/safety. Privacy is articulated as a concern that must be given up for support to live in one’s home. Implicit in this argument is that privacy cannot be enjoyed by everyone; those in need of support or care must relinquish aspects of their privacy. Given the creative possibilities and achievements of technological innovation, this simplistic exchange theory is perplexing.

In order to develop generative ways of thinking about privacy and to discover how technology can enable it for older adults, we must understand what is at stake. It has been argued that privacy is not only about physical space or the nature of information, but it is also about subjectivity (Cohen, 2013). It relates to experienced self-hood that is based on the ongoing, socially situated process of self-formation and individuation (Cohen, 2012). This would explain why it is important to understand how passive monitoring technology affects older adults’ ability to keep personal matters to themselves and prevent experiences of private-life intrusions. Cohen (2013) explains: “Privacy shelters dynamic, emergent subjectivity from the efforts of commercial and government actors to render individuals and communities fixed, transparent, and predictable. It protects the situated practices of boundary management through which the capacity for self-determination develops” (p. 1905). Put simply,
“Claims of privacy invasion are claims about unwanted subjection to the knowledge or power of others” (Cohen, 2012, p. 125). We might think about this more concretely in terms of the actual practices of older adults. For example, in a multicountry study of technology for older adults, users of PERS that allow them to push a button carried on their neck or wrist to reach a telecare operator in an emergency responded to questions about privacy by explaining that they would leave the device in a drawer and choose not to wear it when they did not want that service. The study’s authors note “this is less easy with more totalizing or passive systems” (EFORTT, 2011, p. 17). How less easy this is in practice should be examined if we are to follow Cohen’s dynamic explication of privacy as “an interest in breathing room to engage in socially situated processes of boundary management” (Cohen, 2012, p. 149).

Thinking of privacy in terms of boundary management is compatible with what we have learned from previous research, namely, the significant role of interpersonal relationships in older adults’ lives and decisions, as well as their evolving subjectivities and diversity of privacy concerns. The analysis offered below is enriched by the conceptualization of privacy as boundary management. Interviews were conducted with older adult residents of subsidized independent living residences, family emergency contacts, and residence staff who use a sensor-based passive monitoring system. A full description of the system and processes of use are offered in the Results section of this article because these details are a key component of privacy considerations.

Design and Methods

The study site is six low-income independent living residence apartment buildings of 150–300 units each that are located in a single metropolitan area of the United States. The buildings are owned and operated by a nonprofit senior service organization that had offered residents a sensor-based remote monitoring system on a voluntary basis for 6 years. The system consists of five motion sensors and a heat sensor installed in specific locations within each of the apartments. Resident adopters are required to have two family members or friends serve as emergency contacts. Emergency contacts receive alerts from the telecare center and act as first responders. Both emergency contacts and social workers receive a daily summary e-mail (see Figure 1) and have log-in web-based access to information collected by each sensor by hour. Emergency contacts were not provided with extra training on what to do with information they accessed. The housing organization fully subsidizes installation (~$200) and monthly fees for the system (~$85); residents pay between $5 and $25 per month for the service. Human Subjects Approval was obtained from The Committee for Protection of Human Subjects, University of California, Berkeley, in October 2012.

Participants and Recruitment

I sought to include all users and former users of the passive monitoring system, including residents, primary family emergency contacts, and staff. A list of participants by type is provided in Table 1. I conducted interviews with 41 participants out of a possible total of 48 who met the inclusion criteria. Current user residents, residents who had discontinued use, and emergency contacts were each interviewed once and staff members were each interviewed twice for a total of 49 interviews.

All 10 staff who had contact with the technology participated. Fifteen of the 23 current users as of the start of the study were invited and all agreed. Eight of the current users were excluded: four due to language barriers and four due to serious health issues and/or dementia that social workers determined would impede participation. All eight residents who had discontinued the system within the past year were invited and three declined to participate. Eleven family members who served as emergency contacts were interviewed. Family member participation was lower than that of the residents because some residents declined consent for me to contact them, citing desire for their emergency contacts not to be burdened. Residents who were offered the passive monitoring system and refused it were not interviewed because the social workers pushed back against attempts to identify nonusers, explaining that they were still “working on them” to convince them to adopt and an interview might interfere with a potential decision to adopt in the future.

Fifteen resident participants had incomes between $29,000 and $36,120; five participants had incomes less than $18,050. The majority of the residents had completed high school, some had no education, some had some college education and two had a bachelor’s degree. Each had multiple chronic conditions. More than half (12) had a home aide and 4 had round-the-clock care with overnight aides.

Staff members were recruited to participate during a routine meeting. I presented the study’s purpose and asked that staff contact me if interested in learning more about
participation. Social workers contacted their current client users and those who had discontinued over the previous 12 months for permission to give me their phone number, so I could invite them to participate. Family members were contacted by the same process with the consent of resident participants.

**Data Collection and Analysis**

The interviews were semistructured in which each primary question was asked in flexible order depending on how the participant responded to previous questions and the organic flow of the interview. The interview guide provided in the Supplementary Appendix illustrates the exploratory questioning. The same questions were addressed in interviews with all participant groups to understand multiple perspectives on issues of adoption decision making, processes of use, experiences of use, and perceived benefit. I conducted interviews in person except for five interviews with family members by phone. In-person interviews with residents and emergency contacts took place in resident apartments and restaurants. Staff interviews were conducted in their private offices with closed doors. I interviewed each staff member twice in order to fully understand their processes of use. With permission, interviews were digitally recorded.

I conducted the analysis and extra steps were taken to maintain rigor and accuracy. To stay close to the data, I transcribed interviews verbatim within a week of the interview. Staff responses provided in the first interviews were discussed and confirmed with staff in the second interviews. This process of “member checking” allowed for the refinement of tentative interpretations and further clarification by staff who discussed a broader range of experiences and expressed more ambivalence than did residents and family members who discussed only their own direct experience with the technology, as well as their interactions with acquaintances who had refused it. Social workers were interviewed twice to capture the full range of experiences they had with residents and the technology. I spent 6 months at the site, allowing for the building of familiarity and comfort with staff and residents, and time to ensure I had consistent information about processes of use, as well as access to residents who had discontinued as this was not immediately granted by staff. Rather than using theoretical sampling, I interviewed everyone who had any contact with the system, who could be interviewed, and who agreed to participate. Additionally, all interviews were coded beyond the point of conceptual saturation to reduce potential for coder bias and to ensure that all voices and a full range of privacy articulations and their relative emphases within this sample were incorporated into the analysis. Throughout the data collection and analysis period, I wrote methodological and theoretical memos as records of the development of analytic ideas as well as to refine the interview guide for the second interview with each social worker (Glaser & Strauss, 1967).

Transcripts were imported into Dedoose, software that facilitates the management of qualitative data. I employed the multistep coding processes of grounded theory but did not adhere to grounded theory in its pure form. For instance, both because privacy is highlighted in the literature and because social workers noted privacy concerns in our first interviews while discussing the very low uptake, I made sure to capture perspectives on privacy by asking about it directly to allow each participant the opportunity to speak to it, rather than allowing the topic to emerge organically in each interview. Consistent with a grounded theory approach, I conducted initial coding after each interview and allowed this to influence subsequent interviews. For example, after social workers started explaining in the first interviews that they developed practices to protect residents’ privacy, I adjusted my interview guides with social workers and other participants to ask more direct and specific questions about actual practices in order to understand those practices in relation to privacy.

I used “open coding” to start analyzing the interviews in an evolving process, delineated concepts, and identified their dimensions (Corbin & Strauss, 2008; Glaser & Strauss, 1967). In order to track and organize emerging concepts in a meaningful way, I wrote memos and developed a codebook with working operational definitions that evolved throughout this initial coding process. Examples of open codes are privacy invasion as deterrent, anticipating concerns and comparison with a camera. I then identified themes through “axial coding” in which categories of codes were connected, so dominant themes could emerge to produce an explanation of the situation (Corbin & Strauss, 2008). Themes emerged, such as monitoring movements in the home is a violation of privacy and privacy is preserved through relationships. After generating the list of themes, I reread all interviews and noted instances of evidence consistent or inconsistent with those themes. As part

<table>
<thead>
<tr>
<th>Participant group</th>
<th>Number of participants interviewed</th>
<th>Average interview minutes</th>
<th>Women</th>
</tr>
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<tbody>
<tr>
<td>Residents: age 87 (65–103)</td>
<td>20 (5 discontinued)</td>
<td>65</td>
<td>19</td>
</tr>
<tr>
<td>Emergency contacts: sons, daughters, sisters, granddaughters</td>
<td>11 (2 discontinued)</td>
<td>56</td>
<td>8</td>
</tr>
<tr>
<td>Staff: social workers and supervisors</td>
<td>10</td>
<td>210 (3.5 hr) in two interviews</td>
<td>6</td>
</tr>
<tr>
<td>Total</td>
<td>41</td>
<td></td>
<td>33</td>
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</tbody>
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* All but two staff were interviewed two times; two supervisors were interviewed only once because they did not have regular interactions with residents who use the system and all of their knowledge and experience with the system could be discussed in a single interview.

*Table 1. Study Participants*
of this process I compared and contrasted themes across individual interviews according to the constant comparison method (Glaser and Strauss, 1967), which allowed for differences and contradictions within participant groups, as well as within an individual interview or set of interviews. This is an important step because it allows the analyst to see difference and inconsistencies where they may be unexpected (Clarke, 2005). Indeed, divergent articulations of the relationship between privacy and passive monitoring emerged and each is presented below.

### Results

#### Alert Follow-Up Processes

Social workers who worked from offices in the independent living residences played a key supporting role in the use of passive monitoring. They were responsible for introducing the system to residents and obtaining their consent to install it. Social workers strove to explain to residents and family members what information the system collects and how it is accessed, often by showing them the output on their own computers. Residents signed consent forms after a social worker described the system as thoroughly as they thought appropriate, using words they believed the resident would comprehend. Feedback was not sought from the residents about the extent to which they comprehended this information. Emphasis was placed on the idea that the system would alert a caregiver should the resident be in an emergency and unable to push the PERS button. Computer screens were used as visual aid, but forms with information were not provided and residents received no training as the system requires no activity on the part of the resident. Social workers were aware that some residents who consented did not understand fundamental aspects of the system, and it was revealed during interviews that one third of the study participants who use the system were not aware in that moment that any information about them was being tracked.

Social workers were prohibited from serving as first responders for liability reasons, but they received daily e-mails about the activity levels of the residents and could log in to a web-based site to view activity level data. A screenshot of an e-mail with information provided daily to emergency contacts and social workers is shown in Figure 1. Emergency contacts were first responders to calls from the telecare center. Signals trigger when sensor data indicate that there is (a) a possible bathroom fall, (b) no bedroom exit, (c) the ambient temperature is above or below the set threshold, (d) significant low level of overall activity, or (e) significant change in nighttime bathroom use. When a signal is triggered a telecare operator calls the resident, followed by an emergency contact. If no one answers the calls, the telecare operator continues to reach the emergency contacts. The exceptional response is that the operator will call Emergency Medical Services if sensors on the door and in the bathroom detect no activity after bathroom entrance.

After the situation is resolved, the telecare operator summarizes the event in notes that are e-mailed to the social work staff. Social workers are expected to follow up on telecare center calls with a phone call to residents to confirm that the situation is resolved.

Social workers describe their follow-up conversations with residents as an individualized process. The social worker who had the most clients who used the system described her own procedure of asking three questions during her follow-up calls:

- The first thing is “what is the reason that you go to the bathroom?” And then if they tell me any reason about infection or the pills not working, I have to make sure they go to see doctor...And the third thing is the relationship or social, emotion – or maybe she drank a cup of coffee late. This part, I will [only] understand a little bit but these first two I must cover.

She gives the example of bathroom alerts: “they stay in the bathroom for too long of a time and we ask why – they fell asleep on the toilet – and then we have to know why, ok not sleeping well. So to dig why this happened that you either don’t come out or you go there very frequently, and discover we actually find out a lot of reasons.” The knowledge social workers learned about residents was gleaned from conversations that were made possible by the passive monitoring system. They reached a level of understanding resident activity far beyond the telecare operator’s distinction between needing or not needing immediate help.

### Privacy Articulations in Marketing

Privacy is highlighted in the passive monitoring system’s marketing materials and in the housing organization’s flyers placed throughout the residence buildings. A 2013 promotional video addresses the concept in this voiceover: “Residents continue to go about their normal routine with their privacy intact.” It then advertises the accessibility of data: “staff can monitor resident activity anywhere any time from a pager, a computer, or a mobile device with an internet connection. Empowered with the information that [the system] provides, staff can proactively intervene to safeguard residents.” Concern over privacy intrusion is anticipated and dismissed.

While closing the privacy question with a declarative may be effective for marketing, passive monitoring clearly raises privacy concerns for some people, such as those who may feel that staff and family members knowing—“anywhere, anytime”—how often and when they use the bathroom or get up in the morning is an invasion of their privacy. Among those individuals who social workers offered it to, typically because they had a recent health event or change in health status, the average rate of adoption was 2%. Chief among the reasons for low uptake cited by social workers, as well as current and former resident users, was that it would be intrusive or violate privacy. In fact, some who did adopt...
later discontinued because they found it uncomfortable to have the housing organization staff aware of their movements. If privacy is said to be kept intact in theory but the technology is rejected by 98% of residents who frequently cite privacy concerns, what does privacy mean in practice? Below, I present the ways in which privacy is articulated by staff and residents.

Privacy in Practice
Residents who did not adopt the technology (98%) or who discontinued it (20% of users) felt it was intrusive and a threat to their privacy, whereas residents who adopted and kept it did not feel it violated their privacy. Between the nonusers, discontinued users, and current users, residents articulated multiple interpretations of privacy. Each will be discussed.

Monitoring Movements in the Home Is an Invasion of Privacy
A common reason for residents to decline the technology was concern over privacy. As a social worker put it, “they don’t want people in their business.” A former user explained that most residents she knew had PERS and did not opt for passive monitoring because “they feel it’s an intrusion.” Based on her experience as a discontinued user, she describes who it might work well for: “I think if people aren’t bothered by being monitored or followed [laughs] it’s really good. Someone who has a routine and they don’t mind that there is an agency that’s aware of their movements in the apartment.” Privacy concerns lead to nonadoption even in situations when need appears high. For example, a resident who had fallen in the bathroom and banged on the bathroom walls to get the attention of a neighbor told the social worker who offered the passive monitoring system “I don’t believe in that. I will wear my PERS.” When residents imagined their privacy would be violated by the use of passive monitoring, social workers were unable to convince them to adopt.

Privacy Is Intact If Alternatives Are Less Private
The idea that privacy was not an issue because the system did not provide visual images of their bodies—that it was not a camera—was the most common response from the current 15 users and family members (“I was thinking on it but they cannot see you naked”). Family member emergency contacts agreed that privacy was protected because “they can’t see anything.”

Some social workers and resident users also explained that passive monitoring was preferable to having a home aide or moving to a care facility. One social worker described how some residents weigh their options: “You know the stranger comes to you, do some personal stuff for you, gives you a shower. Everybody does not accept, but passive monitoring is a solution for those people.”

Some current users also responded to the question of privacy by asserting their vulnerability. One replied, “I wouldn’t think that way. We’re old people after all. We got them considering the emergency situations that may happen to us.” Another woman with a home aide 8 hr a day who was unable to flip the light switches on her lamps due to arthritis replied, “Because it’s so desperate to need help and not have it so I’m grateful for anything.” For those who feel unsafe being alone or that having an aide in their home is too intrusive, any intrusion of privacy caused by passive monitoring was a nonissue.

Privacy Is Preserved in the Presentation of Data
A common idea among social workers was that they protected the privacy of residents by regulating the ways in which they followed up on the information collected by the system. This came down to the specific words they choose as well as the reasons they gave residents for checking in.

Word choice was a sticky issue. Residents were easily turned off by the obvious options and social workers struggled by trial and error to find the terms that would sit well with different users. A social worker explained:

Because at the beginning, resistance from them to participate is still the “monitor.” Then it was “who monitors us?” They are very sensitive about the word that we use. Let’s not use “monitor.” Check? “Who is checking?” I tried: “I have noticed or it seems from the system…” and then they will ask you “what do you mean by system?” And then I realize oh, I cannot use system. Then at the end, we felt there are no more words for us to use!

Another explained that there was no impact on a resident’s privacy if follow-up was handled tactfully: “no impact on privacy], but for a not intelligent worker it could. If someone said ‘I saw you went to the bathroom!’ Only because of the way it’s presented. Otherwise no, it’s a tool. I cannot say to the client ‘I checked on you.’”

Social workers were not trained to follow up in a particular way, given scripts, or told what to ask the residents or how to explain why they were calling. One explained: “We were told we have to follow-up but the way to follow-up is important in my opinion. You don’t make them feel like you’re spying on them. It’s important the way you present your findings.” The examples she provided of how best to follow-up involved not disclosing that she had viewed information provided by the passive monitoring system. Instead, she offered excuses for checking in:

I observed a woman in the bathroom 8 to 10 times a night. I called her into my office and she came to my office and I said “You look pale have you slept well?” Of course I won’t say I watched you go to the bathroom. I brought her to the point where she went to see the doctor. They found that two medications prescribed by different doctors were having the same effect and that was the problem. That I feel I was proud I was able to find this.
Being “tactful” by concealing that the passive monitoring system prompted the check-in prevented the system from being “intimidating” to residents. When system-informed concern is wrapped in an excuse to check-in, social workers reported that some residents appreciated their concern and were willing to talk to them about their situations, without knowing the cause for concern. This detective work was felt to be a skill to be proud of because it preserved relationships with residents and sometimes uncovered new information that social workers could use to promote behaviors.

Workers were not comfortable concealing their motive from all of the residents. As one put it, “It feels better if there’s a reason to call for Lorraine because she’s independent. I hate to say this but you can almost get around telling someone who’s not clearheaded: ‘did you eat?’ But for someone like Lorraine, it would be like lying. I feel obligated to tell her the reason I’m calling.” It should be noted that dementia is not signaled by her use of “not clearheaded” and that only one of the current users expressed signs of dementia. Another worker agreed that it should be an individualized approach. In response to the question, _when you call a client after seeing something on [the system], do you tell them that’s why you’re calling?,_ she said “Most the time I say… it depends on who the person is. If they’re happy with the system I’ll remind them they have it. If they’re not…[trails off]. If they ask ‘why are you calling anyway?’ or ‘why would you think I wasn’t sleeping well?’ – then I’ll tell them.” At times, the social workers quietly engaged relatives who had access to the same activity information: “I talk to the client’s son: ‘I found this, when you talk to your mom don’t tell her, but find out how she feels.’” Social workers negotiate and manage privacy boundaries on behalf of some of their clients by concealing what may be experienced as overstep.

The concern that one’s privacy will be violated is not always distinguishable from the concern that one does not understand what information the passive monitoring system collects and how it is communicated. The reason for withholding motives for checking in is also based on doubt that a resident “gets it”—not just how it will feel in practice to be called and questioned, but how the system basically works. For the purposes of this research, I requested access to each current user’s alert records and one third of the residents were unable to consent because they did not comprehend that information could be accessed about them. One woman who was happy with the system responded:

> no, he [my son] doesn’t look at that [online]. I don’t want him to look at that. I don’t want them to know all my business but they know the refrigerator, you know. _Interviewer: So be doesn’t have…_ I don’t know, he may go online, I don’t know if he can see it. That I don’t know. Can they go online? I’m not telling them. Let them find out themselves. Maybe they do I don’t know I can’t tell you because no one has ever said how come you went out that early?

Residents generally comprehended the telecare aspect of the intervention, but not the prevention component that involves the tracking by hour of activity and designation of normal and nonnormal ranges of activity. A social worker explained, “Sometimes I do not think they understand.” Despite their efforts to explain in simple terms and use their computer screen reports to show residents what the system entailed, social workers struggled to achieve comprehension with the residents.

**Privacy and Incidental Findings**

A related issue is the discovery of incidental findings upon following up on data. The potential for this to create tension has been raised in the literature (Mortenson, Sixsmith, & Woolrych, 2013). An incidental finding could lead to a useful intervention, or it could reveal an aspect of a resident’s life that she prefer be kept private. Most social workers described incidental findings with some ambivalence. They discovered a variety of things, such as pets and resident sleeplessness due to distressing arguments with adult children. A social worker described an incidental finding:

> She has a unique way of drying her clothes with the fan on in the bathroom and sometimes that generates an alert because it thinks that the resident is the bathroom for that long. So then we found out that she washes her you know personal items, she dries them with the bathroom fan on. So sometimes you get more than what you want to know about the clients [laughs]. But when she understood why we were concerned she was fine with it.

When asked to compare the claims of the company’s promotional video that it keeps privacy intact with their experiences, this social worker replied with a long pause, then explained:

> Um…it does, it keeps their privacy intact but I don’t know what they mean by the word privacy… I don’t see it as keeping it very private because the social workers know what’s going on in your life and the first respondents know what’s going on in your life. Like I know that Mrs. H washes her stuff with her hands and dries it up on the fan.

Another contacted a resident in response to an alert for no bathroom exit:

> Do you think it’s normal to be in the bathroom more than an hour? If not for the system alerts, we would not know that she loved to take long bubble baths. So we offered a handle in the bathtub and she accepted it. When it [telecare center] called, she was upset because it made her get out of the bathtub. I went to her apartment and observed the bathtub and I said why don’t you have a handle? I made it sound like everyone has one, even me. I don’t want anyone to know I have a goal behind it.
Incidental findings could lead to an intervention that residents feel good about, though it depended on the social worker whether the resident was told what was learned about them that motivated the intervention.

“Yes But No”: Ambivalent Perspectives on Privacy

Not all social workers felt unequivocally that the alert system constituted good practice. Although social workers were told to start their days by logging into the system to check activity level signals, one explains why she refuses: “honestly I feel I don't need to know this. I have other things to do. I mean it’s independent living. Some people just get up early. I don’t ask, ‘why did you get up so early?’ ‘why did you take a long shower?’ Interviewer: do you respond to nighttime bathroom activity changes? It’s not a nursing home. Maybe someone has a stomach flu. It shouldn’t be our interest.” She asserted, “I’m an employee but I also want to give you my perspective. Nobody wants to talk about the bad side. It’s like that everywhere. Researchers too. It’s easy to kind of distort. It’s easy to disregard the critical thinking,” This social worker’s participation in passive monitoring caused her to question the ultra-positive images of technological success projected by the housing organization.

Others expressed ambivalence. For instance, one explained that when she calls people because they “spend too much time in the bathroom,” they get annoyed sometimes: “I felt like I was invading their privacy but then... [silent].” Another echoed this concern: “Some don’t like the idea of people knowing how many times they use the bathroom and are embarrassed if they have diarrhea: ‘I really don’t want to talk about it.’” In response to the question about privacy being kept intact, another said, “As much as you can possibly keep it private. Someone getting calls about bathroom visits might not feel that privacy is intact.”

The nature of their relationships factored heavily. Another social worker replied “mmmmm... yes but no” and noted that it is her relationship with residents that protects their privacy: “In a sense yes, privacy is intruded. Yes. That's why it is very important to have a human here, to have the bonding, a bridge, so many years that they know us, we know them, that some think they would rather tell us than their children.” The theme that privacy is protected through relationship was articulated by each worker, and to a lesser extent by residents. A resident explained that her son will call her when she uses the bathroom a lot at night to ask “what were you doing last night? [laughs].” She explained why it does not bother her: “My son knows me. My children think it's good for me.”

Residents’ relationships with emergency contacts and social workers both enabled and were intensified by the use of passive monitoring; however, social workers were not in touch with every aspect of residents’ personal lives. A discontinued user raised this issue:

In my mind, it didn’t occur but if I had company or friends coming over, particularly a male friend, it might bother me although they don’t know there is anybody here. Do you know, do you know what I’m saying? They don’t know, there could be ten people here, there could be an orgy in the living room [laughs]. But still. It still bothers me that I’m being monitored.

Each social worker was asked if residents had ever expressed concerns about intimacy. Interestingly, all but one social worker interpreted intimacy to mean being getting dressed. Only one staff member understood intimacy to mean sexual intimacy and said, laughing, “certainly you might get a call and say you know is everything okay? But at that point you can say you know ‘everything’s fine.’ But here that would be, but that is a really big hypothetical, it would be such an outlier, but I’m not sure it would be worth saying that privacy can be an issue. I think.” Close relationships did not necessarily create shared interpretations and understandings of boundaries related to privacy. That is, although the nature of one’s relationship to a resident can prevent the violation of privacy, even these relationships have limits. Family and social workers do not know everything, and some residents preferred it this way.

Discussion

This research contributes to the literature on privacy in technology-based care practices with older adults conceptually and through new knowledge about what privacy means to actual users. First, there is no static articulation of privacy’s relationship to passive monitoring. Among this sample of residents, family members, and staff, they include: monitoring movements in the home is a violation of privacy; privacy is intact if alternatives are less private; privacy is preserved in the presentation of data; incidental findings compromise privacy; and privacy is preserved through relationship. These themes lend themselves to the recently developed boundary management framework (Cohen, 2012) that has not previously been applied to care technology research or research with older adults. This framework provokes the useful question of how the introduction of passive monitoring changes boundaries and tools for managing them.

Opportunities for boundary intrusion occurred at multiple points in the processes of passive monitoring use. Residents were held accountable for their movements and activities in their homes by three parties: the operator, family members, and social workers. Residents were asked to answer for activity that fell outside their normal ranges, leading to the discovery of private activities and situations. Social workers sometimes felt the need to make up excuses for checking in because they feared embarrassing residents by knowing what the system is designed to tell them. Absent full information about (a) what information is collected and
who accessed it, and (b) knowledge of when it is being used to understand their situation, residents are under the illusion that their privacy is secure behind a set of boundaries they believe they control. Both the control and feedback enabling principles for privacy design solutions offered by Bellotti and Sellen (1993) were often violated. These are fundamental criteria on which opportunities for boundary management are built; residents who are provided feedback about what and when information about them is accessed by whom and how it is used are empowered—or potentially burdened—with that feedback to adjust their behavior and interactions according to their privacy needs. Recall one user’s confusion: “I don’t know, he may go online, I don’t know if he can see it. That I don’t know. Can they go online? I’m not telling them. Let them find out themselves. Maybe they do I don’t know I can’t tell you because no one has ever said how come you went out that early?” Consent procedures to enable basic aspects of control, coupled with feedback given by social workers at follow-up about what information has been accessed is a social solution to this unresolved fundamental privacy issue. Social workers agreed that privacy would be violated if the use of passive monitoring were not voluntary; there should be a strong relationship between informed consent and voluntary use.

The technology company’s marketing materials claim that this new knowledge empowers staff, and indeed some social workers took pride in the ways in which they leveraged it as tool for detecting unknown issues. Social workers came to know intimate details that residents were reluctant to share with their own family, yet not all social workers wanted their relationships with clients affected in this way. Social workers also struggled to manage different boundaries for each of their clients without overstepping. This was not always successful because social workers were not aware of the privacy needs of each resident. For staff, negotiating and managing boundaries on behalf of residents was a mixed bag.

In practice, older adults and social workers express diverse approaches to privacy. If privacy is integral to one’s subjectivity and is the protection from “unwanted subjection to the knowledge or power of others,” then it is important that boundaries be under the control of residents of independent living. If individuals are informed about the source of concern when alert follow-up calls are made, they would be able to appreciate what it means to be monitored in this fashion and thereby able to determine where their boundaries lie and how and when to negotiate changes. The diversity of privacy articulations and concerns points to the need for opportunity for boundary management to be employed as both a technical design and social practice principle.

Limitations and Future Research

Learning about privacy articulations directly from those who never adopted the system, possibly because of privacy concerns, would have strengthened this research. Residents who discontinued, current users, and social workers provided information about why some residents chose never to adopt the system. This study took place in six independent living residence complexes owned by the same nonprofit organization and located in a single metropolitan area. Experiences of privacy may differ in other environments.

These findings also raise a number of questions. For instance, what is the relationship between older adults’ level of understanding about what the system does and their privacy concerns? A minority of residents supported the idea of privacy as a trade-off (“we’re old people after all”), and yet these residents did not fully comprehend what data were collected and who accessed them. Systematic research on this issue is needed, along with comparisons of family and older adults’ boundaries regarding use of remote monitoring technologies. Finally, in other organizations where staff do not prioritize the ability to remain in independent living, incidental findings or knowledge of falls could negatively affect residents’ tenancy. The current study indicates that each of these issues is an important area for future research.

Supplementary Material

Please visit the article online at http://gerontologist.oxford-journals.org/ to view supplementary material.

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