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**Decision Making and Use of Remote Monitoring Technology
in Low-Income Independent Living Residences**

by

Clara Warner Berridge

A dissertation submitted in
partial satisfaction of the
requirements for the degree of
Doctor of Philosophy
in
Social Welfare
and the Designated Emphasis
in
Women, Gender and Sexuality
in the
Graduate Division
of the
University of California, Berkeley

Committee in charge:

Professor Andrew E. Scharlach, Chair
Assistant Professor Adrian Aguilera
Professor Sharon Kaufman
Professor Charis M. Thompson

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Abstract

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Doctor of Philosophy in Social Welfare
and the Designated Emphasis in Women, Gender and Sexuality in the Graduate Division

University of California, Berkeley

Professor Andrew E. Scharlach, Chair

Passive monitoring systems installed in the homes of older adults have been proposed as a way to revolutionize home healthcare by enabling earlier detection and prevention of health events and delaying health related relocation; however, the processes and social implications are poorly understood, uptake is low, and these purported benefits have not been fully realized. This study combines data from 47 interviews and system alert records to understand lived experiences with the technology of ethnically diverse older adults, family members and staff of low-income independent living residences. A sensor-based passive monitoring system has been on offer to residents as a voluntary subsidized intervention for six years. This study examines the 1) processes involved in decision making about adoption and discontinuation, 2) the procedures of using the technology, 3) experiences with and articulations of privacy, and 4) how participants assess the usefulness of this passive monitoring system.

The three papers that comprise this dissertation are outlined below. They provide complementary presentations of my analyses of the most significant findings that correspond to the study's primary research questions. The three papers examine the following:

1) Resistance on a spectrum: Shaking the 'pro-adoption bias' in studies of passive monitoring and aging. Given the low uptake of passive monitoring, the concerns, needs and perspectives of users, nonusers and former users is a rich area for inquiry. In this first paper, I present the range of ways older adults relate to passive monitoring, including experiences of adoption, nonadoption, discontinuation and creative 'misuse.' The priorities of users (e.g., safety, privacy, control, contact) are shown to be more diverse and multi-faceted than those of the housing organization and family members (e.g., safety, efficiency). The tension between needs, desires, and the daily lives of older adults and the technological solutions offered them is made visible by their active appropriation of and resistance to them. The broad spectrum of resident resistance challenges the dominant image of passive subjects of a passive monitoring system that is designed with little room for resistance or creative use, exposing the active and meaningful qualities of older adults' decisions and practices.

2) Breathing room in monitored space: Opportunities for privacy in boundary management. While scholars have been quick to note that privacy intrusion is a primary issue to be explored with the use of passive monitoring, academic writing about how privacy is impacted

has be limited by our conceptual tools. Information privacy has been the focus of study to the exclusion of personal privacy. In this paper, I examine the ways in which privacy in passive monitoring practices is articulated by participants. These findings reveal where breathing room is eclipsed and where changes to passive monitoring design and practice could create opportunities for residents to manage their own boundaries.

   3) Calculating risk and the management of living: Social workers in a bind. In the final paper I describe the practices and rationalities formed around the selling of the passive monitoring technology to independent living residents who were largely uninterested. Data reveal that the pressure exerted on social workers by their supervisors trickled down into negotiations with residents over adoption. These findings highlight the importance of understanding and respecting older adults' reasons for nonuse as well as relieving frontline staff from having to navigate untenable paradigms in the name of independent living technology.

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Acknowledgements

I am indebted to a number of people who supported me in this dissertation work. First I would like to thank my Chair and mentor, Andrew Scharlach for his encouragement, trust and investment in my intellectual growth. He helped me to shape and clarify the ideas presented here, helped get me to conferences, and opened a door to the study of technology by connecting me to Steve DeMello. I hadn't a clue how much I would learn from Steve when he took me on as a graduate student researcher at CITRIS.

My committee members have been immensely helpful and pleasurable to work with. Sharon Kaufman, Charis Thompson, and Adrian Aguilera each provided critical feedback and unique insight, from study design through chapter drafts. Numerous researchers with experience in the methods and device category I studied shared their practice wisdom during my design phase. Kalpana Shankar was particularly insightful, and Irwin Epstein opened my eyes to opportunities in the analysis of existing data that I would have otherwise missed. Conversations with Jodi Halpern were rich and idea-sparking. I am grateful to David Lindeman who has been generous with his time and constructive feedback.

I would like to thank my dear friend and collaborator, Marty Martinson, who reminds me in overwhelming moments why I am excited about our field and models thoughtfulness in both her research and teaching. My departmental colleague, Mimi Kim, gave me invaluable moral support and I continue to learn from her excellent writing and community organizing. Cathy Covey, Leslie Harlson, Rachel Kaplan and Khawer Khan have also helped me along the way. I thank Shawna Sherman for taking interest and connecting me to those who introduced me to my field site. Jessica Chun was a research assistant of dreams who brought her research experiences with older Korean adults to bear on the interviews she conducted in Korean. James Meadows, thank you for responding to my fledgling dissertation question with "I would read that."

This study's participants were generous with their time. I am especially appreciative of the social workers who made time for me on multiple occasions during their hectic work days and the residents who were willing to discuss their experiences, perspectives and vulnerabilities.

I would like to thank my family for their unwavering support. I won't forget the day my grandmother called to tell me that she had asked my mother to print her a copy of my paper and she was in the middle of reading it: "I'm enjoying it and though I don't fully understand everything in it, I get the general gist of what you're saying. I just think it's wonderful that you can do something like that." I'm truly grateful for the support I have had to do something like this.

Introduction

Over the past 30 years, aging in place has become part of the "common lexicon" of gerontology researchers and professionals (Pynoos & Nishita, 2007, p. 185; Vasunilashorn, Steinman, Liebig, & Pynoos, 2012). Built into the idea is that the ideal place for older adults to live and receive care if necessary is in one's home as opposed to a residential care setting. This belief is supported by research findings that indicate that the vast majority of older adults wish to remain living in familiar environments, even if they acquire an illness, and prefer living independently (Gibson 2000; Rubinstein, Kilbride & Nagy 1992; AARP, 2005). The desirability of aging in place is based in part on the supportive role played by the long-term home through familiarity, place attachment and the maintenance of resident identity (Rowles, 1993). It is believed that aging in a familiar environment is adaptive and promotes independence; benefits that are often contrasted with the stress caused by relocation in old age (Rowles, 1993). The term "independent living" may be the most common tagline segment used in advertisements by companies providing residential housing for seniors. In addition to the housing milieu, independence and independent living are promoted by health, social service and policy-related not-for-profit organizations, government, and private foundations. In this sense, independence has become "institutionalized" (Portacolone, 2011, p. 804). Aging in place and independent living are the dominant normative themes in gerontology research and public policy applied for the promotion of in-home remote monitoring.

The underlying economic logic of aging in place and independent living is tied to the forecasted "care crisis" or "care gap." It is widely held that the gap between the rising need for care and declining supply of care providers, both family members and professional nonrelatives, is a result of the demographic shift to an older population. The United Nations estimates that between 2010 and 2050, the worldwide population of people 65 and older will more than double, while the population 80 and older will nearly triple (Mattke, Klautzer, Mengistu, Garnett, Hu, & Wu, 2010). Long-term care innovation has become a focal issue for many countries that are experiencing a dramatic demographic shift to an aging population and significantly higher rates of chronic illness and disability (Brodsky, Habib, Hirschfeld, & Siegel, 2002). The structure and low pay of home care jobs has created a workforce shortage, and many countries are turning to immigrant and migrant workers who may tolerate poor working conditions to fill those positions (Mattke et al., 2010). Recruitment and turnover are persistent problems. The availability of informal family care has been on the decline for many decades in some countries, and has begun more recently in others (Mattke et al., 2010).

The Technological Fix

Over the past two decades, technology has been increasingly featured in the English literature on 'aging in place' (Vasunilashorn, Steinman, Liebig, & Pynoos, 2012). In the context of discourses on the neo-liberalization of healthcare and the demographic shift to an aging population, technology-based home care services are positioned as a possible solution to the problem of decreasing resources and increasing demand for care for chronic conditions (Oudshoorn, 2011). In the U.S., 13% of the population is 65 years of age and older, and is projected to grow to 20% by 2030 (US Census, 2009). An increasing number are living with chronic health conditions. Arthritis affects 58.6% of this population, 19.7% have diabetes, 59.2% have hypertension, and 21.9% are obese (Lafortune & Balestat, 2007). The disability rate for

those 65 and older is 16.6%. The number of disabled elders is expected to increase by between 35% and 50%, depending on the survey consulted for past trends (Lafortune & Balestat, 2007). Examples of crisis framing in technology reports and research literature abound. The preface of a 2010 RAND Health report, title "Health and well-being in the home: A global analysis of needs, expectations, and priorities for home health care technology" begins with this declaration:

> Experts agree, in principle, that the current model of care delivery is ill equipped to deal with future challenges, particularly the rapidly increasing demand for care due to an aging population and improved survivability of many diseases. They also see the potential value of home health care technologies to relieve pressure on health care systems because of their ability to substitute for expensive and scarce professional labor and to promote a shift in care from high-cost institutions to patients' homes. These changes not only would decrease cost and improve the sustainability of health care systems but would also be consistent with patient preferences for more active aging, which includes greater independence and involvement in care decisions and delivery. (Mattke, Klautzer, Mengistu, Garnett, Hu & Wu, p. iii)

The search for a solution in the form of technology is a widespread phenomenon; governments in North America, Europe, New Zealand, and Australia have identified technology as a part of their strategy to address the needs of their aging populations (Milligan, 2009).

These technologies are in rapid development with multiple generations of telecare, telehealth and smart home devices on the market and an evolving language to describe them. The range of in-home care technologies is wide and includes environmental controls, remote telecare and diagnostics using webcams and internet-based communication, medication monitoring devices, smart clothing with sensors to monitor heart rate, temperature, and other vital signs, and GPS tagging devices to track an individual's location and movement, in addition to assistive technologies (such as voice recognition software), remote caregiver training technologies, cognitive fitness and assessment programs, social networking programs on the internet, and domestic robots and companion pets (Milligan, Mort & Roberts, 2010; Center for Technology and Aging, 2009).

Remote monitoring (for care) and remote patient monitoring (for medical care purposes) are ICT-based (information communication technology) systems that are the subject of the majority of writing on technological innovation to support independent living and aging in place, with the majority of lifestyle monitoring publications focused on motion detection (Brownsell, Bradley, Blackburn, Cardinaux, & Hawley, 2011). Remote monitoring is an umbrella term that describes a set of technologies such as sensors and motion detectors that collect and communicate data about an individual's status or behaviors (Goldwater & Harris, 2010). Data may include vital signs, falls, location, behavior, gate speed, or environmental temperature. Data recipients are family members, professional and nonprofessional caregivers, employees of call centers, other health care professionals and designated resident building employees, like managers or service coordinators.

The shift from actively triggered social alarms to passive remote monitoring is a significant innovation. In an active monitoring system, the user has to push a button to cause an alert. Passive remote monitoring systems transmit data without the user's action or required awareness. This transition to sensors and other devices that enable position and activity tracking is an important one because it reconfigures the socio-technical practice. These technologies have

the potential to reorganize roles and responsibilities for providing care because the practices themselves are reshaped with new devices serving to mediate care (Oudshoorn, 2011). Sensor system technologies have been proposed as a way to revolutionize home healthcare and are being evaluated for their potential to enhance care management and prevention; enable people to live in the least restrictive environment possible; improve resident safety; increase efficiency of health care by reducing emergency room visits and hospitalizations; provide earlier detection of and improved response to sentinel health events; and contribute to informed, shared decision making regarding health care through the collection and analysis of new data (Skubic et al., 2009; Demiris, 2010).

These benefits remain largely unrealized. The authors of a recent systematic review of home-based lifestyle monitoring technologies conclude that the evidence base for effective use of lifestyle monitoring is relatively weak (Brownsell, Bradley, Blackburn, Cardinaux, & Hawley, 2011). One of the primary concerns cited in the literature is that the development of and research on remote monitoring systems has largely been divorced from social and ethical concerns, as well as needs and perceptions of users (EFORTT, 2011; Courtney, Demiris, Rantz, & Skubic, 2008). Knowledge of social and ethical implications and an understanding of the necessary conditions and processes for successful implementation of RM are lacking, *leading researchers like* Demiris and Hensel (2008) to call for work to fill this well-identified gap: "the research agenda for smart homes must include development of an ethical framework for their design and implementation. Implications, including those for social relationships and interaction, over-reliance, and privacy, must be fully considered" (p. 39).

The proposed research will examine decision making about adoption and discontinuation, use procedures, experiences with and perceived impact of a sensor-based passive monitoring system in six urban, low-income Independent Living Residences (ILRs). It delves into ethical and social implications of this emerging socio-technical practice that are poorly understood, including those for opportunities for privacy, informed consent and self-determination. It is positioned at the interface of multiple areas of inquiry and domains of practice: social and critical gerontology, health technology assessment, care theory, ethics and bioethics, social welfare policy (home care and health care policy and practice), senior housing policy, and gerontological social work practice.

Literature Review

Authors of a recent systematic review of home-based lifestyle monitoring technologies that assessed English language articles between 1990 and December of 2009 concluded that the evidence base for effective use of lifestyle monitoring is relatively weak (Brownsell, Bradley, Blackburn, Cardinaux, & Hawley, 2011). While the review found a steady increase in publications on the topic beginning in 1997, just 4 out of the 74 articles involved studies with more than 20 participants. Forty-nine of the studies focused solely on the development of technology, and of these, motion detection was the most frequently used. The reviewers call lifestyle monitoring "a relatively immature research area in which there is little detailed understanding of how to provide comprehensive and effective systems" (Brownsell et al., 2011, p. 188). Focus group and "living-lab" research has been the most common approach to the study of position tracking remote monitoring with older adults, though pilot studies are becoming more

common. These studies are described in some detail below, followed by a discussion of the literature that addresses ethical considerations.

Establishing Evidence of User Acceptance and Clinical Effectiveness

A pre-post survey was conducted as part of a remote monitoring pilot in 13 homes in rural Minnesota that assessed caregiver burden, quality of life and health related quality of life. Participants were clients of a home-health agency and their family caregivers. All were white and lived in one of three Independent Living Residence (ILR) (rent in buildings ranged from low-income $1,200 to market rate 1,960/mo) but participants' socioeconomic status was unreported. The technology tracked residents' heart rate, breathing rate, gait, ADLs and alert statuses, such as falls. Reports and alert notices were transmitted to professional caregivers and informal caregivers were given status updates on their participating family member. The findings revealed an improvement of quality of life scores using the CDC HRQOL-4 instrument among older adults but no significant change in quality of life for caregivers. Caregivers' scores on the Caregiver Strain Index improved (CSI consists of 13 dichotomous response questions), but improvements on the Caregiver Burden Interview were not statistically significant. A statistically insignificant decrease in number of physically unhealthy days and days in which routines were interrupted by physical or mental health conditions was reported, as well as a slight increase in number of mentally unhealthy days among older adults. (Alwan et al., 2006).

The impact on family caregivers of an online remote monitoring system called Worker Interactive Networking (WIN) has also been evaluated using an employee benefit model (Mahoney, Mutschler, Tarlow, & Liss, 2008). In this study, 19 dyads of working caregivers and their elder family members were given six months of free access to both an online caregiver support group and a remote monitoring system that provided web-based status reports and email or pager alerts. Twenty-seven workers were originally enrolled in the study, but seven elders did not want the remote monitoring technology and one died. Most of the six elders reported concerns about privacy, expressing that the monitoring system would "see them" and "know about their personal activities." Half were concerned about being watched by "big brother". The majority of the decliners also thought that installation would be a hassle (Mahoney, Mutschler, Tarlow, & Liss, 2008). Ninety-five percent of the remaining 19 caregiver participants were white and 90% had at least some college education. Nearly half had incomes greater than $70K, while only 16% had incomes less than $40K.

Of the 19 participants, seven caregivers chose to use the WIN Home Monitoring System. The others chose only the WIN Discussion Group (online caregiver support group). Findings were overall positive: users of the Monitoring System reported higher morale, productivity and stress reduction and ease of technology use at the end of the six-month period. All users of the WIN Home Monitoring system would "definitely recommend the system". Participating elders did not report finding the technology isolating or intrusive. The study's authors suggest that remote home monitoring might become a feasible employee benefit for caregivers (Mahoney, Mutschler, Tarlow, & Liss, 2008).

The At EASE study (Automated technology for elder assessment, safety, and environmental monitoring) involved 3 phases of mixed-methods research within independent living residences (ILR). The purpose was to assess the outcomes, feasibility, and signal reliability and validity of remote monitoring technology in low-staffed senior housing. The first phase was a focus group study with nonusers to assess whether concerns of elders, family members and staff might be

allayed by remote monitoring. Twenty-six participants were involved in eight sets of focus groups within three ILRs (13 residents, 4 family members, 9 staff members). Most residents were widows who had recently moved to be near family. The majority of the residents did not believe monitoring would suit them but did identify residents who they thought needed it. Family members desired minimal alerts and messages but wanted the technology if it could help ensure them that their loved one was doing all right. Participants found the system prototype user-friendly (Mahoney, Mahoney, & Liss, 2009). The authors conclude that those who might most benefit from remote monitoring are individuals who have recently relocated or have forgetfulness, the tendency to fall, have trouble taking medications and walking enough, and those who have "some type of vulnerability or at-risk situation" that have their caregivers concerned (Mahoney, Mahoney, & Liss, 2009, p. 23). Clinicians had a preference for personal visits over remote medication monitoring and were not interested in receiving more data due to feeling overloaded already by computer messaging. The researchers place emphasis on the importance of having a system tailored to the facility and its users (Mahoney, Mahoney, & Liss, 2009).

The second phase involved a test of signal reliability and validity. Of the available sensors, participants used motion sensors in each room, a water sensor in the bathroom, and a system remote to turn the system on and off (it is unclear if residents were the users of this remote). Options that were not chosen by participants were door sensors, pressure sensors for beds and chairs, and automated appliance on/off options. No further information about these preferences is provided. Alerts were triaged to different responders. Families wanted cell phone alerts, staff desired email notifications and building superintendents needed to be paged (Mahoney, Mahoney, & Liss, 2009).

The third phase was a pre-post test of the remote monitoring pilot intervention with 10 sets of resident/family/staff members who used five systems for at least four months. Twenty residents were originally identified by staff as having safety and health concerns. Thirteen of them would not consider participating. The researchers speculated based on staff feedback that these residents had dementia and they or their family members did not want monitoring to identify them as unfit for independent living. Participating residents were white, widowed, with a mean age of 83 and some college education. Two participants failed a screening for cognitive impairment but legal guardians gave their assent for participation. Each resident had moved to the ILR after the death of a spouse to be close to a family member. The majority reported fair health, the rest reported good health, and all reported good or very good emotional health (Mahoney, Mahoney, & Liss, 2009).

No change was found between residents' pre- and post-tests, which indicated that they still thought the system would address their needs, was not intrusive, and would not replace staff. Residents had reported in the pre-test that the intervention would make them feel secure ('strongly agree') but decreased their rating to 'somewhat agree' after receiving the intervention. Six of the 10 family members would recommend the system to others. There was an overall perceived slight worsening of their family member's health, a significant worsening of their perceived emotional health, and slight increase in concern reported in the post test. Family members' worry rate dropped from 50% to 20% and time it took to check on relatives decreased slightly. The staff reported no change or drop in work load. All had reported moderate level of concern for the residents' safety and wellbeing and six of the 10 rated the system high or very

high for addressing these concerns. Eight of 10 would recommend the system (Mahoney, Mahoney, & Liss, 2009).

The Ethical Technology in the Homes of Seniors (ETHOS) group was a project developed by an interdisciplinary team to explore issues of privacy and design in information technology for use in elders' homes. Researchers held focus groups with 57 residents of an affluent retirement home, all of whom were well educated and the majority married (Shankar, 2010). Participants toured a technology-equipped "living lab" designed to resemble a realistic home. After learning about and viewing the devices in the home setting, participants expressed concern that they should be in control of the decisions about who receives what types of data about them. Some identified a tradeoff that they anticipated having to face, between autonomy and privacy. Others expressed fear about passing control over decisions about their lives to family, as well as concern that technology should not replace personal care and human contact. A potential tension was also revealed between the perspective of a caregiver and that of an elder about appropriate granularity of data, such as clarity of monitoring videos. Caregivers were more comfortable with these data than were older adults (Lorenzen-Huber et al., 2011).

What was most apparent to the researchers of the ETHOS project was that the privacy framework they planned to work with could not capture the issues raised by the elder participants. To the surprise of the researchers, participants did not express concerns about seclusion, autonomy, property, spatial, or data protection, and they had "naïve mental models" about information privacy such as type of data collected, storage, data access and potential use (Lorenzen-Huber et al., 2011). They report that privacy preferences of older adults are "balanced against the desire for independent living, personal autonomy, and satisfying relationships" (p.). The researchers highlight the need for work that better articulates privacy for this age cohort (Shankar, 2010).

A study of perceptions of privacy violation among elders using care surveillance in Sweden involveed single interviews with 17 users (Essén, 2008). The technology was a monitoring system that collected "activity data" about elders who wore a wrist device. Two types of experiences were revealed: "care surveillance as enabling – feeling cared for" and "care surveillance as constraining – feeling as if under suspicion." Sixteen participants reported an overall positive experience with care surveillance. Participants described privacy in interesting terms, comparing in-home care surveillance with the perceived alternative of nursing home living where they would be observed and forced to observe others. Privacy was compromised in nursing homes but care surveillance helped elders feel liberated. The option to exit the surveillance service was important to the majority. None of them understood what the sensors monitored or how the data is analyzed, yet reported feeling adequately informed (Essén, 2008).

A study was conducted in two Midwest CCRCs in independent and assisted living units to examine privacy and other factors older adults consider when deciding whether to adopt motion, bed, fall detection, and kitchen safety sensors. Four focus groups were conducted with a total of 11 participants plus 3 who were interviewed. Age is the only characteristic reported for the participants and all were over 65 (Courtney, Demiris, Rantz, & *Skubic, 2008).* The participants described the following factors that would be important in considerations of technology adoption: self perception of health; physical condition; mental and emotional condition; anticipatory living; the influence of family and friends; the influence of healthcare professionals; the physical environment; the technology type; and the perceived redundancy of the technology (Courtney et al., *2008).*

Most participants felt that perception of need would supersede any privacy concerns they had, but very few thought that motion sensor technology would be needed, even after sample scenarios were presented. Image-based technologies were perceived as more obtrusive and less acceptable than others; however none of the technologies were rejected by all participants. Participants described older adults with cardiac, pulmonary, mobility and cognitive disorders as potential users of the technologies but did not feel that they needed the technologies, despite their existing health problems, ranging from serious cardiac and pulmonary conditions, arthritis, history of fractures, joint replacements and falls, and use of oxygen and mobility devices (Courtney et al., *2008).*

A much larger focus group study conducted in the UK shed light on the concerns of multiple stakeholders, including but not limited to the issue of privacy. The twenty focus groups included a total of 186 carers, professionals, and older people (Percival & Hanson 2006). Concerns centered on the following issues: choice and self-determination; privacy & surveillance; human contact & social inclusion; replacement of hands-on care; back-up services; and cost & resource implications. On the topic of choice and self-determination, professionals and carers noted that telecare services could undermine choice and independence by enabling individuals to be dependent (older adults might not bother turning off their taps) or opportunities for risk-taking. Even carers who might be adversely affected by daily risks faced by their family members stated that older adults "have a right to 'take the risk of living the way [they] want to'" (Percival & Hanson, 2006, p. 895). Participants stated that telecare would become like "big brother" if that right were eroded or if people were pressured to use the technology (Percival & Hanson, 2006).

Another concern was raised over confidentiality and the potential for companies to gain access to lifestyle data for marketing use or targeting. Participants were also concerned that governmental departments not gain access and weigh the data against applications for assistance such as attendance allowance. A related concern was that there may be good reason for older adults not to "publicize difficulties" (Percival & Hanson, 2006, p. 898). Participants insisted on the importance of individuals being able to maintain and strengthen human contact and the idea that telecare should not reduce "even more a person's connection with a social world" (Percival & Hanson, 2006, p. 899). It was important also that hands-on care not be reduced by telecare interventions. Participants highlighted the need for sufficient, coordinated back-up services in telecare service and carers worried that they would be designated first responders and viewed as an affordable replacement for formal services. Many believed the central government should pay for telecare but that it should be tested prior to widespread implementation. A related issue was repeatedly raised about the existing under-resourced system of home care (e.g., basic aids, home safety features) and what that might mean for future reimbursement for telecare (Percival & Hanson, 2006).

Hensel, Demiris and Courtney (2006) have drawn attention to the widely reported relationship between usability and obtrusiveness and the emphasis in the literature on the value of home health technology that is "unobtrusive" or "unintrusive". They found that no definition or framework for determining the extent to which a technology is obtrusive/intrusive had been put forth. They developed the following definition of obtrusiveness in home telehealth technology (the definition incorporates the concept of intrusive): "a summary evaluation by the user based on characteristics or effects associated with the technology that are perceived as undesirable and physically and/or psychologically prominent" (Hensel, Demiris & Courney,

2006, p. 430). They highlight the following assumptions built into this definition: 1) The judgment that a technology is obtrusive is based either on cumulative characteristics or on one characteristic of particular importance to a user; 2) Obtrusiveness is subjective and may vary by user; 3) Users include all residents in the home; and 4) The use of telehealth in one's personal home space results in a "different psychological dynamic" than that operating in an institutional setting. Their conceptual model of obtrusiveness (Figure 1) is built on eight dimensions comprising 22 elements identified in their review of the literature on telehealth, which included remote monitoring position tracking and other IT-based systems used for vitals tracking, videophones, and smart home systems (Hensel, Demiris & Courney, 2006). The privacy dimension is conceptualized as invasion of personal information or data and as violation of personal home space. The word independence is included as "symbol of loss of independence" within the dimension of self-concept. Hensel, Demiris & Courtney (2006) present this framework for obtrusiveness as the first step toward the development of an instrument for use in evaluation and design.
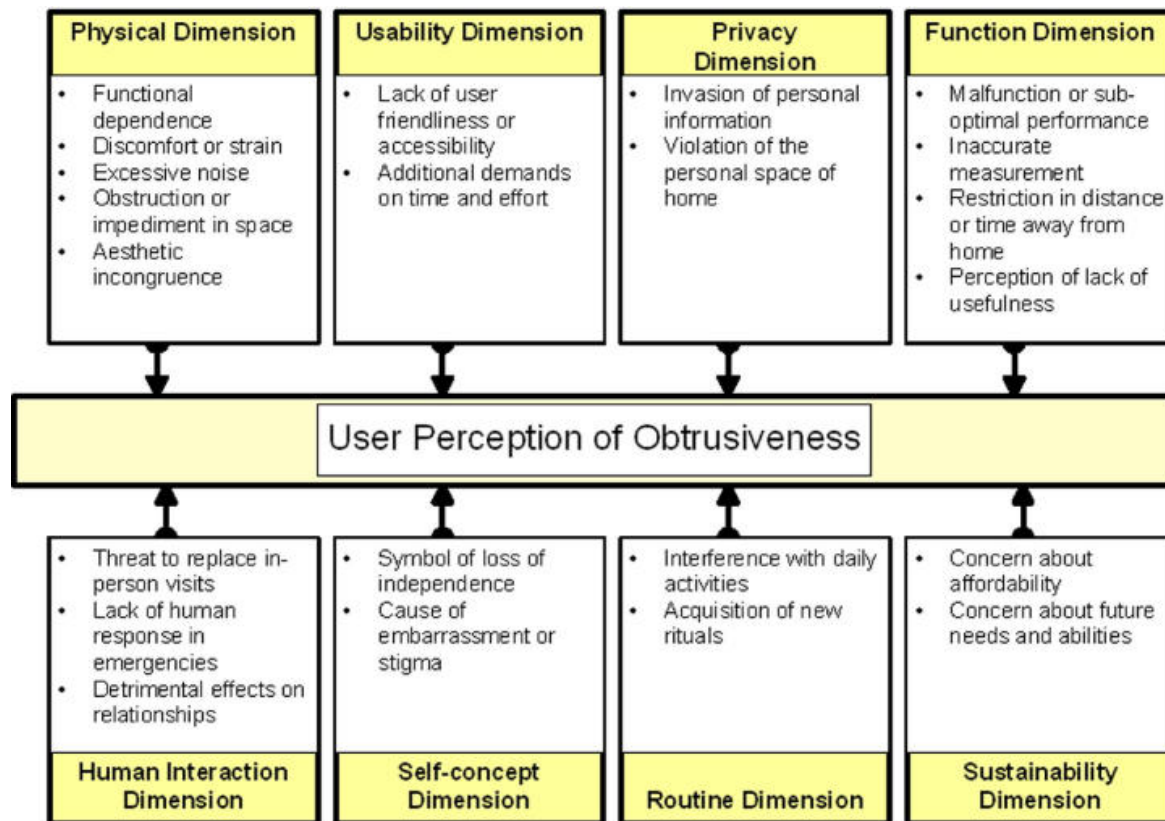
Figure 1

Figure copied from Hensel, B.K., Demiris, G., and Courtney, K.L. (2006). Defining obtrusiveness in home telehealth technologies: A conceptual framework. *Journal of the American Medical Informatics Association, 13*(4), pp. 428-431.

Two years later, Demiris and Hensel (2008) published a systematic review of smart home applications, defined as "a residence wired with technology features that monitor the well-being and activities of their residents to improve overall quality of life, increase independence and prevent emergencies" (p. 33). They identified twenty-one smart home projects and reached the following conclusion: "None of the studies present evidence of the effects of smart homes on health outcomes, including earlier disease, illness, and injury detection and intervention. No research was found addressing the effect of a smart home on acute episodes requiring emergency care or a possible delay or prevention of nursing home placement." Demiris & Hensel (2008) call for randomized controlled trials that will become feasible when smart home technologies are more widely implemented.

The reviewers also highlight the issue of unstudied social impact. Demiris and Hensel (2008, p. 39) write that "the research agenda for smart homes must include development of an ethical framework for their design and implementation. Implications, including those for social relationships and interaction, over-reliance, and privacy, must be fully considered" (39). They conclude by writing that design and use of IT-based products for older adults should be based on actual user needs rather than advances in technology and recommend the in-depth study of "technical, ethical, legal, clinical, economical and organizational implications and challenges" (Demiris & Hensel, 2008, p. 40).

The European Commission's Science in Society Initiative-funded EFORTT project (Ethical Frameworks for Telecare Technologies for older people at home) examined ethical, social and gender implications of technological care interventions for elders in Spain, England, Norway & the Netherlands using ethnography, older citizens' panels, and a participative conference. The study process was multi-faceted and will not be described in full. Ethnographic data were gathered in each of the participating countries from a variety of settings and with a variety of telecare technologies, including remote monitoring. Data were also collected from introductory and follow-up older citizens' panels that involved a total of 91 participants at introduction and 75 at follow-up across the four countries (EFORTT, 2011). Key findings from the citizens' panels are that people valued the ability to contact someone in an emergency but had serious concerns that telecare might be viewed as a cost-saving option and could replace hands-on care and that ethical and social issues might be eclipsed by technical, political and economic concerns. Participants also wanted to be involved in all related discussions and "recognized as citizens who had the capacity and the desire to make a meaningful contribution to these debates" (EFORTT, 2011, p. 7).

Independence

Product designers, vendors and policy makers describe remote monitoring technologies as tools to increase independence. Despite its widespread use in aging services and health and home care technology discourse, the concept of independence is complex, highly relative, and very rarely defined. The literature on independence does not reveal a single meaning. Some studies link independence to a single variable, while others employ complex frameworks (Demiris, 2009). No conceptual model for understanding independence among elders and/or people with disabilities has been developed (Demiris, 2009).

Increasing independence is a primary goal for smart home technology, but the achievement of this goal is complicated by the fact that stakeholder groups may attach different meanings to the word (Demiris, 2009). One of the legacies of the Independent Living Movement,

driven by young people with disabilities, is that the meaning of independence lies not in the absence of need for assistance, but rather, in having control over how and where assistance is provided (Morris, 2001). In a review of the literature on independence in old age, Secker et al. (2003) find that the writing on service provision relies heavily on the idea of the ability to function unassisted (to perform ADLs and IADLs). Here, independence is more closely associated with the goal of avoiding dependence rather than having choice and control over the provision of support (Grenier, 2003). This tendency reflects the observation made by Katz and Marshall (2004) that bio-identities in old age are increasingly ranked by functionality and health status, measured by ADL and psychometric assessments. Secker et al., (2003) conclude that understanding independence as the absence of dependence is not the most accurate approach: "While dependence equates with reliance on others, independence can be seen as subjectively self-assessed lived experience. Thus it becomes possible to combine high levels of dependence with high levels of experienced or felt independence..." (p. 375). The values gerontologists have identified indicate that the meaning of independence to older adults is more complex than the absence of dependence (see Kaufman, 1993; Mack et al., 1997).

What is the significance of independence for remote monitoring practices? Demiris (2009) conducted a Delphi study with 53 researchers and system designers and 48 older adults to examine how independence and shared decision making in the context of technology use are defined. The project team reviewed 42 studies on independence to create a list of its dimensions, and from this, developed a framework that "captures independence as a state in which older adults maintain, adjust and process resources (financial, physical, social and other) within a given environment in order to maximize ability for self-care, control and perception of identity" (2009, p. 6434). Smart home technology is a potential mediating factor that could enhance the identified attributes associated with independence (Demiris, 2009). Additionally, the collection of data by smart home devices is a potential tool for information sharing between patient, caregivers and physicians that could enable shared decision making in clinical encounters. Shared decision making has become an "ideal model" for treatment decisions, and the involvement of elders in this process is increasingly considered good ethical practice, yet the meaning of patient involvement in decisions making has not been defined (Demiris, 2009).

The Delphi study revealed that experts and older adults define independence and shared decision making differently. The expert group associated shared decision making with patient education while the older adults defined it as "an active and empowered role in the decision making process" (Demiris 2009, p. 6434). The opportunity for shared decision making was considered important for decisions about treatment options but also for decisions about the use of technology, including which technology is used, its frequency of use, and who has access to the collected data. In addition to these issues of control, informed consent, choice, and ongoing feedback emerged as important elements (Demiris, 2009).

Ethical Considerations

In the first published book to address bioethics and aging, Moody (1992) writes that the dominant model of bioethics is based on the doctrine of informed consent, which upholds the ideal of autonomy and is oriented to actions, such as critical events in acute care settings that require immediate decision making. The dominant model of bioethics is guided in large part by legal concepts and legal instruments (i.e. power of attorney and guardianship) in which the notion of autonomy and rights are central. The free and rational subject of procedural liberalism

and social contract theory, with its "fetish of autonomy," fits poorly within chronic care situations (Moody, 1992).

In a review of the literature on ethics and remote monitoring of older adults through 2010, Bowes, Dawson & Bell (2012) find that detailed consideration of ethical issues is lacking and addressed only "obliquely and superficially" (p. 8). In Rowan and Mynatt (2005) privacy and obtrusiveness is briefly discussed in relation to the idea of "a sweet spot of utility and acceptance" (p. 522 as cited by Bowes, Dawson & Bell, 2012, p. 9). Bowes and colleagues comment on this idea: "[it] acknowledges a central ethical difficulty in finding an appropriate balance between benefit and harm to the individual, but fails to appreciate the difficulty in identifying a single 'sweet spot'. Clearly, the perceived location of this varies according to the stakeholder group, and there are important ethical questions around whose views should prevail and in what circumstances" (2012, p.9). The dearth of publications that explicitly discuss ethics in RM leaves much unresolved.

To address the issue of informed consent, Bruce (2012) has developed a formal framework for evaluating the appropriateness of sensor-based monitoring technologies. The article, published in *The Gerontologist,* includes a flowchart that begins with the question "Does the older individual pose a risk of harm to self or others" and continues through a series of yes or no questions. The final question is "What impact does the technology have on the older person's quality of life (judged according to the surrogate)?" This question has three options that lead to the following definitive resolution "it should not be used" or to these affirmative 5 criteria for use: 1) Honoring older individual's informed decision, or surrogate determines that it is a: 2) Greatly effective monitoring technology; 3) Minimally obtrusive; 4) No greater obtrusiveness than necessary; and 5) Reassesses in timely manner" (Bruce, 2012, p. 5). This framework is intended to help caregivers navigate this uncharted territory with confidence that they are doing so in a way that is ethical.

Informed consent is only one of many ethical issues arising from PM. Bowes et al. (2012) argue that issues of surveillance and passivity of monitoring, cognitive impairment, cost to individuals, and use of lifestyle monitoring data require detailed attention. They raise questions about the impact of monitoring on the tension between safety and control, motivation for self-care, frequency and quality of human interaction, personal identity and well-being, and ownership and use of new data under privacy rules that may or may not cover them. An important ethical question is how these new data will be kept secure and managed under existing health data regulations or new policy.

McLean (2011) raises additional and overlapping ethical concerns. Regarding challenges to personal identity, she underlines the problem of visible devices acting as a public marker of need. It is also possible that RM might reduce human contact, provide poor care or false assurances about health and well-being that could result in missed diagnoses (her example is the flu, unseen through a telecare device and undetected by automated questions). The remote monitoring of behavioral biomarkers for detection of cognitive impairment raises its own set of ethical questions pertaining at this stage to researchers of the technology, such as is the patient's wish for confidentiality respected regardless of cognitive decline and who should receive the new information (McLean, 2011)? In the practice settings of health and social services, case loads are often too large to be handled with a high degree of care. In this context, people experiencing cognitive decline may more easily lose their right to self-determination and personal freedoms. Citing Rose (2001, p. 3), McLean warns, "As some social critics have

reminded us, preventive practices in a risk-adverse society can lead to expulsion of those deemed less fit and to a collapse of consent into compulsion" (p. 323), noting that at the other extreme are new possibilities for enabling people to maintain a level of privacy that would be lost in residential nursing facilities.

Writing on the broader topic of "welfare technology" as it is called in Scandinavia, Hoffman (2012) raises additional questions: *who is responsible for using them? How might they alter family responsibilities and relationships, and do they induce significant stress?* He also notes that surveillance is based on an idea of what counts as "normal activity." Who decides what counts is an important ethical question (Hoffman, 2012). Mortenson, Woolrych and Sixsmith (2013) have expressed concern over behavior alteration: "The idea of monitoring deviations from 'typical' activity patterns for an individual has interesting parallels with the process of institutionalization, where the expected patterns become the specific norms against which activity and behavior is evaluated. The individuals being monitored may begin to change their behavior if they are concerned about the feedback and implications of their actions, such as triggering alarms, warnings, and contact from caregivers" (p. 10). Power relations are likely to be impacted by passive monitoring and need to be examined so as to prevent practices that may be experienced as disempowering (Mortensen, Woolrych, & Sixsmith, 2013; Sixsmith, 2013).

Summary of the Findings

What we know most definitively is that prospective users do not want PM to reduce social interaction, replace human contact, or replace hand-on care (Lorenzen-Huber et al, 2011; Percival & Hanson, 2006; EFORTT, 2011). In practice, users may not find PM isolating (Mahoney, Mutschler, Tarlow & Liss, 2008). It is evident that older adults are unlikely to be fully knowledgeable about what type of data is collected about them, its storage, analysis, and use, all while reporting that they feel adequately informed (Lorenzen-Huber et al, 2011; Essen, 2008). Older adults want control over decision making on issues of who has access to what data collected about them under which conditions (Demiris, 2008; Lorenzen-Huber et al, 2011; Percival P Hanson, 2006; EFORTT, 2011).

Reducing caregiver burden is a potential advantage of PM. Two studies reviewed here showed a decrease in worry and safety concern among family caregivers, higher morale and reduced strain, (Alwan et al, 2006; Mahoney, Mahoney, & Liss, 2009), and one indicated no workload change for professional caregivers (Mahoney, Mahoney, & Liss, 2009). Family caregivers, on the other hand, have expressed concern that PM would place greater burden on them to act as first responders (Percival & Hanson, 2006).

Studies indicate that need may supersede privacy concerns (Courtney et al., 2008) and that users do not find PM intrusive (Mahoney, Mutchler, Tarlow & Liss, 2008; Mahoney, Mahoney & Liss, 2009). The experience of being under surveillance appears to be more often felt as care than constraint (Essen, 2008). On the other hand, the assessment of need is contested (Courtney et al., 2008), and focus group and pilot study participants express fear that PM will reduce privacy, act as "big brother," or undermine elders' power to keep information about themselves private for their own reasons (Mahoney, Mutschler, Tarlow, & Liss, 2008; Percival & Hanson, 2006).

Findings from these studies illustrate what Lehoux (2006, p. 61) calls the "dual performative potential of health technologies." Duality refers to the coexistence of positive and negative effects, or advantages and disadvantages of health technology, which may act to

reinforce/weaken identity and kinship, decrease/increase or facilitate/impede autonomy, power, knowledge and uncertainty, risks, and so on (Lehoux, 2008; 2006, p. 61). The dual performative potential of remote monitoring further complicates the diverse landscape of meanings associated with independence and shared decision making (Demiris, 2008) and multi-dimensional concepts like privacy. For example, technology is commonly described as a tool to enhance independence, yet older adults and caregivers have also expressed concerns about PM undermining independence, self-determination and choice (Percival & Hanson, 2006).

A number of ethical values have been discussed but not fully addressed. It appears that older adults will trade privacy for autonomy, though assessment of need may be a point of disagreement. We lack a privacy framework that captures older adults' concerns related to passive monitoring. Researchers have voiced concern about the potential for behavior alteration and the collapse of consent into coercion, among other anticipated issues.

Limitations of the Research

Remote monitoring technologies for use in individual's homes are a relatively recent development. The fact that this technology has not yet been mainstreamed makes it difficult for researchers to identify an adequate number of active users to serve as study participants. The remote monitoring device and associated services are not systematically reimbursed through public or private insurance plans, so researchers have relied heavily on prospective user and small pilot studies where the technology is provided for a period at no cost to participants.

Potential users have been asked in focus groups to discuss sample case scenarios and answer questions about their perceptions and acceptance of the technology. With the exception of one component of the EFORTT collaboration, the research has not been ethnographically motivated and the majority of gerontology studies have not been conducted in real-world environments (Mahoney, 2011). Private living units are where people interact with the technologies and where those technologies are expected to work. Ray and Qayum (2010) remind us that the private home is a legitimate and important site of study where power relations, such as those based in class/caste, race/ethnicity, and gender, are produced and experienced. Age relations might be added to this list, in light of the fact that older adults are *visited by* more often than they make visits to the homes of younger adults, making elders' homes locations in which to observe social relations of power and other revealing dynamics.

Pilot studies have collected health metrics and care burden and satisfaction surveys. Pre-post studies provide descriptive quantitative findings because most have sample sizes too small for statistical analysis. The findings are not generalizable and most approaches have not involved sampling for range, so we know very little about user acceptance and outcomes for elders and caregivers who are of any race or ethnicity other than white. When participant income is reported by authors, the samples are comprised of economically-advantaged participants.

Gaps in the Literature

Privacy is often taken in the literature as something older adults willingly trade for autonomy (Townsend, Knoefel & Goubran, 2011), yet studies describe highly contextualized, diverse and subjective views of privacy held by older adults (Lorenzen-Huber et al., 2011). It has largely been assumed among researchers that privacy would be the biggest concern and barrier to PM use among older adults but researchers have found that existing privacy frameworks do not adequately capture concerns expressed by participants (Lorenzen-Huber et al., 2011).

There is evidence that the influence of and concern for others matters to older adults in decision making about PM use (Lorenzen-Huber, Boutain, Camp, Shankar, & Connelly, 2011; Courtney et al., 2008) and that relationships are a critical component of this socio-technical practice that are not well understood. Largely missing from the literature are descriptions and analyses of real-life decision-making processes and the domestication of remote monitoring when it has been introduced into an elder's home. The ways in which remote monitoring technology influences care practices are even less well understood.

The Current Study

The current study takes up multiple issues where they stand according to the literature. In recognition that many of the ethical considerations that have been raised must be understood in relation to actual practices and procedures that develop around the technology, the study takes place in a real-world non-pilot environment in which a passive monitoring system has been used for 6 years. It focuses on processes and procedures of use. First, in order to learn about motivations, interactions with family members and professional caregivers and desires and perceived benefits, decision making about adoption will be examined. Second, decision making is taken to be an ongoing process; residents decide to continue using it or to discontinue it. This study examines users' assessment of usefulness over time, revealed in part in their actions, interactions and resistance to the system. Privacy is also examined because the extant research has not thoroughly drawn out articulations of privacy (Shankar, 2010). Designers and engineers will struggle to integrate privacy options into their products if terms of privacy are not worked out. The disconnect Mittelstadt and colleagues note between privacy theory and applied research may prevent the development of passive monitoring technologies that meet the privacy needs of older adults.

This dissertation project examined the experiences of older adults who live independently and are offered the option of using sensor-based passive monitoring technology, as well as experiences of their family and professional caregivers. Participants are social workers, housing and technology staff of six subsidized independent living residence buildings and current resident users, former users and their family members who serve as emergency contacts. The primary research questions are:
1) What are the processes involved in decision making about adoption and discontinuation and who participates in what way?
2) What are the procedures of use by social workers and family members?
3) How is privacy in relation to passive monitoring understood and experienced by participants?
4) How do residents, social workers and family members experience passive monitoring and assess its usefulness?

Each question is addressed in the three papers that follow, organized according to the primary themes that surfaced: resistance and multiple forms of use (research question 1 and 4), privacy (research question 2 and 3) and social workers' techniques to sell (research question 1).

Methods

Data were gathered using in-depth semi-structured interviews in English and Korean with elder residents, family members and technology and social work staff working at six urban low-

income independent living residence apartment buildings. The buildings were owned and operated by a senior service organization that offered residents the option of adopting a sensor-based remote monitoring system. They had offered the system for six years at the start of the study. This was not a pilot and glitches were worked out long before this research began. The system consisted of five sensors installed in specific locations within their apartments. Adopters were required to have two emergency contacts willing to respond to alerts generated by the system's telecare center. The housing organization fully subsidized installation (~$200) and monthly fees for the system ($85); residents paid between $5 and $25 per month for the service. This study was approved by University of California Berkeley's Committee for the Protection of Human Subjects.

Participants

A total of 47 interviews were conducted with 41 participants: 15 current user residents; five discontinued residents; 11 emergency contacts; and ten staff members. Out of a total of 41 participants, the majority (33) were women, and half (22) were foreign born. Interviews with three residents who discontinued the technology and one emergency contact whose mother discontinued were conducted in Korean. All other interviewers were conducted in English.

Fifteen of the 23 current users in the six buildings were invited to be interviewed and each agreed. Of the eight who were excluded, four did not speak English or Korean and four had serious health issues or dementia that social workers determined would impede participation. Of the current user residents who participated, seven were U.S. born and white, one was African American, two were born in Poland, one in Puerto Rico, one in Peru, one in Malaysia, one in Japan, and one in China. Five of eight residents who had discontinued within the past year were interviewed. Three of the eight who were invited refused: two spoke Chinese, one spoke Korean. Of those who had discontinued use of the technology, three were Korean born, one was U.S. born and white, and the fifth was born in Czechoslovakia. Three of the six buildings where residents lived were low income tax credit buildings and the other three were HUD Section 8. Fifteen participants had incomes between $29,000 and $36,120; five participants had incomes less than $18.050. The majority had completed high school. Some had no education, some had some college and two had a bachelor's degree. One resident was male. All residents were U.S. citizens. Participating residents were age 65 to 103 with an average age of 87. More than half (12) of the residents had a home aide helping them for between four hours a week and 24 hours a day seven days a week. Four residents had this round-the-clock care with over-night aides. Each resident had multiple chronic conditions.

Eleven emergency contacts were interviewed. Fewer emergency contacts than residents were contacted because residents were asked permission to have their family member contacted and four did not grant it. Most cited not wanting to burden their children. Emergency contacts included four foreign born and seven US born daughters, sons, a granddaughter, sister and home aide: six white, one African American, one Japanese American, one born in China, one in Korean, one in Guyana, and one in India.

All technology, housing and social work staff participated. The ten staff members included three US and seven foreign-born participants from Russia, China, Israel, India and Korea. All social work staff were women (6) and all housing and technology staff were men (4).

Procedures

Staff were recruited to participate during a routine meeting. I presented the study's purpose to learn about decision making and use of passive monitoring and asked that staff contact me if they may be interested in participating. Each did and social workers contacted their current client users and those who had discontinued over the previous year for permission to give me their phone number so I could invite them to participate. Social workers also called their clients' emergency contacts to briefly describe the study and obtain permission for me to contact them directly.

The semi-structured interviews were conducted in person with the exception of five interviews with family members conducted 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. Interviews addressed a range of questions, including the process of decision making about adoption and discontinuation, perceived usefulness of the technology, and processes of use. Interview questions were guided by the research questions and focused on procedures and experiences with decision making about use and discontinuation, procedures of use of the system generally, knowledge of residents about what data the technology collects and who receives it, experiences with privacy, and assessment of usefulness. The questions were addressed in interviews with all participant groups to understand multiple perspectives on the same issues.

Analysis

The grounded theory method was used to analyze the data in an evolving process as it was collected (Glaser & Strauss, 1967; Corbin & Strauss, 2008). Throughout the data collection and analysis period, methodological and theoretical memos were written as records of the development of analytic ideas (Glaser & Strauss, 1967). The immediate transcription of interviews allowed time for reading and memo writing prior to the subsequent interview. The transcribed interviews and memos were analyzed for concepts and possible themes using open coding into Dodoose. At this stage concepts were delineated and their properties and dimensions were identified (Corbin & Strauss, 2008). Codes were derived from the data and were modified throughout this process; corresponding memos were filed by these codes. Axial coding was used to reassemble the data and relate concepts to each other to produce an explanation of the situation (Corbin & Strauss, 2008). After generating a list of themes, all interviews were reread and instances of evidence consistent or inconsistent with the themes that emerged were noted.

Overview of the Three Papers

The three papers that comprise this dissertation are outlined below. They provide complementary presentations of my analyses of the most significant findings that correspond to the study's primary research questions. The three papers examine the following:

1) Resistance on a spectrum: Shaking the 'pro-adoption bias' in studies of passive monitoring and aging. Given the low uptake of passive monitoring, the concerns, needs and perspectives of users, nonusers and former users is a rich area for inquiry. In this first paper, I present the range of ways older adults relate to passive monitoring in low-income independent living residences. This includes experiences of adoption, nonadoption, discontinuation and creative 'misuse.' The priorities of users (e.g., safety, privacy, control, contact) are shown to be more diverse and multi-faceted than those of the housing organization and family members (e.g.,

safety, efficiency). The tension between needs, desires, and the daily lives of older adults and the technological solutions offered them is made visible by their active appropriation of and resistance to them. The broad spectrum of resident resistance challenges the dominant image of passive subjects of a passive monitoring system that is designed with little room for resistance or creative use, exposing the active and meaningful qualities of older adults' decisions and practices.

    2) Breathing room in monitored space: Opportunities for privacy in boundary management. While scholars have been quick to note that privacy intrusion is a primary issue to be explored with the use of passive monitoring, academic writing about how privacy is impacted has be limited by our conceptual tools. Information privacy has been the focus of study to the exclusion of personal privacy. In this paper, I examine the ways in which privacy in passive monitoring practices is articulated by participants. These findings reveal where breathing room is eclipsed and where changes to passive monitoring design and practice could create opportunities for residents to manage their own boundaries.

    3) Calculating risk and the management of living: Social workers in a bind. In the third and final paper I describe the practices and rationalities formed around the selling of the passive monitoring technology to independent living residents who were largely uninterested. Data reveal that the pressure exerted on social workers by their supervisors trickled down into negotiations with residents over adoption. These findings highlight the importance of understanding and respecting older adults' reasons for nonuse as well as relieving frontline staff from having to navigate untenable paradigms in the name of independent living technology.

Paper 1: Resistance on a spectrum:
Shaking the 'pro-adoption bias' in studies of passive monitoring and aging

INTRODUCTION

A significant innovation in independent living technologies is the shift from actively triggered social alarms to passive remote monitoring. In an active monitoring system, the user has to push a button to cause an alert. Passive remote monitoring systems transmit data without the user's action or required awareness. Remote monitoring is an umbrella term that describes a set of technologies that collect and communicate data about an individual's status or behaviors (Goldwater & Harris, 2011). Data may include vital signs, falls, location, activity, gait speed, or environmental temperature. Data recipients are family members, professional and nonprofessional caregivers and health care providers, employees of telecare centers, and residence building employees. Sensor-based passive remote monitoring systems collect and analyze bio-behavioral markers and deviations from normal behavior, such as a change in number of bathroom visits, which are communicated to an emergency contact for interpretation as signs of a possible problem. They have been proposed as a way to revolutionize home healthcare (Skubic et al., 2009; Demiris, 2010).

Gerontological research tends to construct elders as passive recipients of care and promote the idea of care as a problem for caregivers, care systems, and policy, an approach rooted in the medical model (Dannefer, Stein, Siders, & Patterson, 2008). In the context of discourses on the neo-liberalization of healthcare and the demographic shift to an aging population, technology-based home care services are positioned as a possible solution to the problem of decreasing resources and increasing demand for care for chronic conditions (Oudshoorn, 2011). Passive monitoring technologies are being evaluated for their potential to enable people to live in the least restrictive and least expensive environment possible; improve resident safety; increase efficiency of health care by reducing emergency room visits and hospitalizations; and provide earlier detection of and improved response to sentinel health events (Skubic et al., 2009; Demiris, 2010). These interventions are dedicated to the goal of risk prevention.

The focus of research on passive monitoring use with older adults has been cost and clinical efficacy (Greenhalgh et al., 2013), as well as impact on care burden and work productivity (see Alwan, Sifferlin, Turner et al., 2007; Mahoney, Mutschler, Tarlow, & Liss, 2008), with more recent focus on acceptance of the technology by older adults and caregivers (see Mahoney, Mahoney, & Liss, 2009). Uptake in the U.S. has been very slow but appears to be increasing in senior living organizations (LeadingAge & Ziegler, 2013). One of the primary concerns cited in the literature is that the development of and research on remote monitoring systems has largely been divorced from social concerns and an understanding of the perceptions, needs, and desires of older adults (Greenhalgh et al., 2013; EFORTT, 2011; Courtney, Demiris, Rantz, & Skubic, 2008). For example, increasing independence is a primary goal for this technology, but the achievement of this goal is complicated by the fact that stakeholder groups may attach different meanings to the word (Demiris, 2009). The perspectives of users is a rich area for inquiry (Demiris & Hensel, 2008; Courtney, et al., 2008; Shankar, 2010; Lorenzen-Huber et al., 2011; Greenhalgh et al., 2013), particularly given the low uptake.

Close study of the ways older adult interact with passive monitoring can reveal user representations, values, goals, and assumptions on which product design and care practices are based (Brown & Webster, 2004; Neven, 2011; Lehoux, 2008). In this study, I examine the range of ways older, ethnically diverse adults relate to passive monitoring in low-income independent living residences. The paper describes how this technological tool to ease care and prolong independence is experienced and shaped by independent living residents. It includes experiences of adoption, nonadoption, discontinuation and creative 'misuse.' The tension between needs, desires and the daily lives of older adults and the technological solutions offered them is made visible by their active appropriation of and resistance to them.

BACKGROUND

The user (and potential user) who consumes a particular product is the primary subject of interest within the fields invested in the study of technology. Usability studies of Human-Computer Interaction focus squarely on the user or potential user. Satchell and Dourish (2009) write that in the eyes of product developers, the user is not a morally neutral subject, but rather, is shaped either as a good user who adopts and uses according to design or a bad user who does not. The moral user can be observed in language employed in research on passive monitoring with older adults, in which authors link terms of noncompliance, generational incompetence and paranoia to participants who refuse to use the technology. Other forms of use are similarly marginalized, for example, when users actively adapt the system to achieve social contact, this is framed as "misuse" (EFORTT, 2011, p. 21). In similarly paternalistic terms, when older adults express disinterest in technologies, designers and providers might frame this as "initial" resistance (Neven, 2011). A problem with all of this language is that it is dismissive of rather than inspired by actions that indicate practices and ambitions that extend beyond pre-defined, interpreted "needs" (Peine, Rollwagen, & Neven, 2014).

Science and Technology Studies (STS) scholars have shown a growing interest in how nonuse constitutes something more than "negative space" (Satchell & Dourish, 2009). Careful not to fetishize nonuse, they are beginning to use it as an analytical tool to understand sociocultural and sociotechnical contexts and normative assumptions about what it is to be a user, illustrating how nonuse can be "active, meaningful, motivated, considered, structured, specific, nuanced, directed, and productive" (Satchell & Dourish, 2009, p. 15). Satchell and Dourish (2009) articulate the need to study nonuse on its own terms, as well as take up ethical and methodological responsibilities toward users, which entails taking them seriously:

> As an ethical concern, it suggests that we should take people's concerns as primary rather than attempting to interpret them as providing support for one sort of potential product or another; and as a methodological one, it highlights the important things that we might miss if we are attempting to read all responses to technology purely as expressions of potential interest or potential adoption. (p. 15)

In a similar vein, researchers on the multi-country EFORTT study to develop an ethical framework for care technology use argue that respecting 'reshaping' is an ethical imperative: "people's creativity in customizing systems is actually essential to the 'ethical' use of telecare and this customization process should be respected. In this way telecare systems (in design and implementation) can avoid becoming totalizing and coercive" (EFORTT, 2011, p. 16). Diverse

forms of use do not necessarily point to failure, but rather, are integral to ethical socio-technical practices.

Diverse forms of use and nonuse also provide insight into which problems the technology is set up to solve and which it does not. Mort, Roberts and Milligan (2011) warn that the foregrounding of technological 'solutions' may "impoverish both the design and implementation of care services for older people" (p. 154). They note that care as monitoring is a (presumably) cost-effective but over-simplification of care, with consequences for elders' psychological and physical well-being. Greenhalgh and colleagues (2013) describe the literature as "framed mostly in the abstracted, rationalist language of gathering, transmitting and processing data," to the exclusion of additional contextualized processes and relationships, while in reality, "it involves practical and moral choices that take account of the (personally meaningful and socio-culturally framed) particularities of the situation" (p. 87). The growing collection of behavioral and biometric data and rationalist logic that are part and parcel of the "technologisation of health" evoke a "logic of choice," whereby added data is equated with added value, and which Mol (2008) has contrasted with a more desirable "logic of care." Addressing these reductive representations of care is complicated by the fact that theory is nearly absent in the literature on technology and aging (Sixsmith, 2013). The lack of theory stems from the fact that rationalist logics concerned with efficiency do not easily lend themselves to questioning.

Evgeny Morozov (2013) recently coined the term "technological solutionism" to describe the ideological approach to complex social phenomena as "neatly defined problems with definite, computable solutions or as transparent and self-evident processes that can be easily optimized—if only the right algorithms are in place!" (p. 5). Quoting design theorist Michael Dobbins, he explains, "solutionism presumes rather than investigates the problems that it is trying to solve, reaching 'for the answer before the questions have been fully asked.' How problems are composed matters every bit as much as how problems are resolved" (p. 6). The critique of technological solutionism is not anti-technology, but rather, anti-reductionist. Morozov (2013) writes: "There are other, more fruitful, more humanistic, and more responsible ways to think about technology's role in enabling human flourishing, but solutionists are unlikely to grasp them unless they complicate their dangerously reductionist account of the human condition" (p.14). He suggests that designers and engineers would do better to understand "the complex practices that our reality is composed of" (p. 13).

In contemporary gerontology in which the definition of old age is contested and ways of being an older person are said to be expanding (Jones & Higgs, 2010; Gilleard & Higgs, 2010; Philipson, 1998), ways in which elders interact with technologies and their built-in assumptions and expectations should be a treasure trove of expressions of identity and meaning making about topics of interest (e.g., independence, independent living, care). To analyze these interactions, I employ the insight that values are embedded in technology and technology reinforces values (Lehoux, 2006). For example, gender relations and technology have been positioned as intertwined and mutually shaping in technofeminist scholarship. The mutual dependency and fluidity of gender relations and technology (Wajcman, 2010) reveals the values and assumptions upon which technology is designed and serves as a model for how we might study values and assumptions embedded in technology for older adults. This idea that technology and users are co-constructed also frames older adults and caregivers as potentially active and capable of shaping the technology's meaning and use in daily life (Brown & Webster, 2004).

This analysis of diverse forms of use of passive monitoring technology is offered in the spirit of promoting technology to support human flourishing. The aim of this paper is to examine what researchers, practitioners and designers can learn about the shortcomings revealed in the narratives and practices of users, creative users, dissatisfied former users, and nonadopters of passive monitoring technology intended to enable independence in a setting where approximately 98% of residents declined the technology and 20% discontinued. This study highlights the gap between what is desired by residents of independent living and what is promised by passive monitoring – a gap explained by older adults' diverse and complex approaches to independence that cannot be easily rationalized or technologized.

METHODS

Data were gathered using in-depth semi-structured interviews with elder residents, family members and technology and social work staff working at six urban low-income independent living residence apartment buildings with supportive services. The buildings were owned and operated by a senior service organization that offered residents the option of adopting a sensor-based remote monitoring system. They had been offering the system for six years in June 2013. This was not a pilot and glitches were worked out long before this research began. The system consisted of five sensors installed in specific locations within their apartments. Adopters were required to have two emergency contacts willing to respond to alerts generated by the system's telecare center. For a detailed description of the methods, see the Methods section of the Introduction.

A total of 47 interviews were conducted in English and Korean with 41 participants: 15 current user residents; five discontinued residents; 11 emergency contacts; and ten staff members. Fifteen of the 23 current users in the six buildings were invited to be interviewed and each agreed. Participating residents were age 65 to 103 with an average age of 87. Eleven emergency contacts were interviewed. Emergency contacts included daughters, sons, a granddaughter, a sister and a home aide. All ten technology, housing and social work staff participated.

The semi-structured interviews were conducted in person with the exception of five interviews with family members conducted 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. Interviews addressed a range of questions, including the process of decision making about adoption and discontinuation, perceived usefulness of the technology, and processes of use. The questions were addressed in interviews with all participant groups to understand multiple perspectives on the same issues.

The grounded theory method was used to analyze the data in an evolving process as it was collected (Glaser & Strauss, 1967; Corbin & Strauss, 2008). The transcribed interviews and memos were analyzed for concepts and possible themes using open coding into Dodoose. At this stage concepts were delineated and their properties and dimensions were identified (Corbin & Strauss, 2008). Codes were derived from the data and were modified throughout this process; corresponding memos were filed by these codes. Axial coding was used to reassemble the data and relate concepts to each other to produce an explanation of the situation (Corbin & Strauss, 2008). After generating a list of themes, all interviews were reread and instances of evidence consistent or inconsistent with the themes that emerged were noted.

FINDINGS

The Passive Monitoring System: How Information Flows

This system is a two-part intervention with a telecare response service through a call center and additional information accessible 24-7 to designated users. The alerts are automatically generated through an algorithm and based on a five-sensor system of motion detection. Urgent red signals trigger when sensor data indicate that there is 1) a possible bathroom fall; 2) no bedroom exit; 3) the ambient temperature is above or below the set threshold, or 4) no base station dial-in (the system was based on operation of a phone line; base station would not dial-in if the phone was off the hook or the line was momentarily down). Non-urgent red signals indicate 1) significant low level of overall activity or 2) significant change in nighttime bathroom use. If, for example, the sensors in and around the bathroom detect no activity after bathroom entrance is detected, an urgent red signal is triggered and a telecare operator calls the resident, followed by an emergency contact. If no one answers the calls, the operator calls EMS. In response to all other urgent red signals and a non-urgent red signals, such a significant change in the number of times a resident uses the bathroom at night, the telecare operator continues to try to reach the emergency contacts.

The intervention also includes web-based information features intended for prevention, achieved through the collection and communication of new bio-behavioral data about the resident that includes the six features described above. Additional information is change in meal preparation based on a sensor inside the refrigerator, number of times there was motion through the apartment door, and actual number of nighttime bathroom visits. Data are available 24-hours to emergency contacts and designated residence staff through a log-in website where activity is visually presented by the hour. These recipients also can opt in to have a daily e-mail that summarizes the relationship between the actual activities of the resident over the past 24 hours and the "normal range." The "normal range" is personalizable, within limits, and adjusted at the beginning of use while the system "learns" what a typical activity pattern is for the individual. These data enable recipients to follow-up with the resident about the abnormal activity. In theory, if a resident is using the refrigerator more frequently or infrequently than usual, this may indicate a cognitive change, illness or other medical problem that the resident might not voluntarily report.

"Selling" Passive Monitoring

The housing organization's social workers were responsible for what they called "selling" the technology to its residents (see paper 3 for an analysis). While the word "sell" was used by staff, the organization heavily subsidized the monthly cost of the system (~$85) and the full installation fee (~$200). Residents paid between $5 and $25 monthly on a sliding scale.

Two methods were used to introduce the system to residents: group meetings involving a description of the system and its benefits, often with a peer resident user serving as a spokesperson, and one-on-one meetings between individual social workers and residents with whom they had rapport. Sometimes the group meetings would be simultaneously translated by the social workers while other meetings were language-specific. The system was made available to all residents through these group meetings as well as posted fliers translated in four languages.

Social workers were given a list of characteristics that define an appropriate potential user. These included living alone, having had a recent fall, being 'at risk' of falling, or recently experiencing a health event or change in condition. The vast majority declined the technology. The adoption rate reported by social workers of those who were deemed appropriate users and offered it one-on-one varied between "almost zero" and 25%, with 2% most often reported. In June of 2013, 23 out of 1,075 residents were users (approximately 2%). Six residents, or more than 20% of adopters, discontinued for reasons other than a move or death within a 12 month period. Adoption, nonadoption and discontinuation are discussed below with a particular focus on the unexplored areas of discontinuation and creative use.

Adoption

Residents had a variety of reasons for agreeing to adopt. Most reported that their family member(s) wanted them to use it, and some decided adoption was "the right thing to do" because they wanted to make things easier for their family. Four residents reported that the decision to adopt was made for them by a family member or social worker. Others had reasons of their own, such as beginning to feel vulnerable and having learned that other residents had died in their apartments without a way to call for help. Some had no children living nearby and wanted an emergency response system, while others were not Medicaid eligible and could not afford a home aide. Still some found the passive monitoring system preferable to having a stranger come into their home to help them. Almost half of the total resident population had a home aide; more than half (12) of the residents who were current users had a home aide helping them for between four hours a week and 24 hours a day seven days a week (4). All users had multiple chronic conditions and three of them adopted specifically for the emergency response in anticipation of a diabetic coma, vertigo episodes and asthma attacks.

Each user reported that the passive monitoring system had never helped them in an emergency or potential emergency situation, but most reported that they or their children benefited from the added peace of mind they felt with the technology. Other users were less enthusiastic. When a user whose granddaughter had pushed her to adopt the technology was asked how she felt about the system, she replied, "just normal....well to tell you the truth, I really didn't want it. I figured to me it's like money wasted." Among users who expressed general satisfaction with the system because it provided peace of mind or appeased their family members, many reported that they had been asked by social workers to use the technology for between one and six years before they agreed. This situation, characterized by a long period of resistance followed by adoption, will be referred to as reluctant adoption. The issue of intrusion on decisional privacy and self-determination is discussed in papers 2 and 3.

Non-Adoption

Approximately 98% of the residents who were offered the passive monitoring system declined it. A supervisor expressed puzzlement about nonuse after considering the purported benefits of the system and vulnerability of the residents: "why are they thinking in some other way? I would call it irrational." The most common reasons residents provided for not adopting included not wanting people in their business, identity conflict, the sentiment that "I'm not there yet; it's for frail elderly," mistrust when told the sensors were not cameras, concern that it would needlessly worry their children, the monthly cost ($5-$25 sliding scale), fear of EMS breaking in

when they are not home, not wanting life prolonged when the time comes to die, and feeling that the system did not meet their needs.

Very few residents with Medicaid chose to adopt, citing no added value in the sensor-based passive monitoring system over the personal emergency response system that Medicaid provides free of charge. In order to promote adoption, particularly among those without Medicaid PERS, the organization subsidized the passive monitoring plus PERS but not PERS alone, making PERS twice as expensive as the combined passive monitoring/PERS service. This was a significant financial incentive, but adoption remained low.

Discontinuation: Unwelcome Disruption

Resistance existed on a continuum beyond refusal to adopt and reluctant adoption. Those who agreed to use the system but later had it removed cited some unique reasons, in addition to the same reasons given by those who refused adoption. The most common reason was that the expectation of routine built into the system disrupted their activities and caused behavior change. A number of users who discontinued worried that those activities deemed abnormal within the constraints of the passive monitoring system would disrupt the lives of their emergency contacts, or their own lives should it result in a call from the telecare center. Their concern was often founded; family members were called in the middle of the night to make long drives to check on their loved one and residents were woken from naps by EMS workers pounding on their door when residents missed the initial call. A social worker described the events leading up to one woman's decision to discontinue:

> There is another case where she begged me to withdraw: I told her this is the way it's supposed to work because you really are not feeling well and we find out, so this is working well. Then she was in the bathroom more than one hour. Then she said because she has the constipation, and another problem where she has to soak her hands in the bathtub, so whenever she went in and then the ticking clock started, okay one minute two minute, 'if I don't come out 60 minutes then my children will get the call, then they will come out!' So I changed one hour to 90 minutes and she tried it about three months, but still seeing the same alert. So then she said please please, let me go.

Across the board, residents were sensitive to the possibility that their own vulnerability would translate into burden on family members. Family members expressed frustration with the false alerts, such as when a daughter was frequently called in the middle of the night when her mother fell asleep on the toilet. In this case, as in others, an alternative system was preferred; here, relying on the home aide to contact a family member before leaving for the day if the resident was unwell. In that situation, the daughter could extend the hours of the worker that day or visit her mother without relying on information from an imprecise system.

Disruption of residents' own lives also upset residents. An 85-year-old discontinued user explained: "I said I don't think I can deal with this because I'm not on a schedule. I'm a very irregular person, I get up at different times of the day, I go to sleep at different times of the evening. I use the bathroom at night at least two or three times so they would get signals." Social workers were cognizant of these issues. One described the conflict between expectation of routine and lived realities: "Some of the clients get up from their bed 9:00, another 12:00. They're retired. I want to sleep over 12:00pm: 'don't bother me before 12:00pm', you know? And if the person didn't get up, this is an alert." Another 85-year-old woman with bursitis who had a history of diabetic comas was on the whole was very happy having the system, but annoyed with

it when she slept in and was woken by the sound of her sister yelling into her answering machine. Her sister explained what had become a routine after receiving calls from the telecare center that her sister had not gotten out of bed and was not answering her phone: "I call and I just keep calling and when her answering machine comes on I'll speak to her through that and see if I can get her up." Across the continuum of discontinuing and embracing the system, there were residents who reported regular incidents of unwelcome disruption, though not all actively resisted this by having the system removed.

With the introduction of consequences for residents who stayed in the bathroom for "too long," this room became a space where activities were rushed. It is generally understood that taking extra time in the bathroom is not uncommon for older adults, particularly when washing or soaking wounds and when extra care to avoid slips and falls is required. A discontinued user had taken showers at the "unusual" time of 4:00 a.m., and stayed in the bathroom for longer than an hour. The family members were pleased with the system, but the resident had it removed because she felt hurried in the bathroom. It should be noted that creating the feeling of being rushed in the space where falls are the most common is counterproductive. Notices caused by frequent bathroom use was also a problem for residents: "when an old lady can't sleep she's always going to the bathroom and I can't do that right…I told the social worker. That's why I didn't want to put in the system. Because in the morning they'll call here."

The expectation of regularity of routine that is built into the system coupled with no options for the older adult to control it can present a problem for some users and threaten their autonomy, causing discontinuation, adjusted behavior, or tolerance of disruption. This was reflected by a discontinued user who stated that "a person who is independent might not want it." It is commonly believed that residents forget about the fact that they have a passive monitoring system installed and therefore do not feel the gaze of the system. These findings indicate that alerts triggered by occasional behavior that falls outside a normal range serve as reminders that one will be held to account for deviating behavior. Residents worried that unnecessary alerts would bother family members and expressed a kind of hyper vigilance to avoid them before ultimately making the move to discontinue the system.

Discontinuation: Uncomfortable, Fearful and "Spooked"

Another theme echoed by residents who had the system removed was experiences of fear, discomfort and anxiety. A woman who had the system installed because she felt vulnerable due to poor physical health, discontinued because it caused her anxiety that registered at psychological and physiological levels. Her blood pressure skyrocketed the night the sensors were installed and remained elevated on subsequent checks. She explained to the housing organization's technology representative that there must be some kind of interference between the sensor system and her blood pressure armband that shared an electrical outlet. In retrospect, she realized this was impossible:

> I said, Jeff, that thing is spooking me out. My pressure was fine and then the installer left and I took it and it was high and it was high that night, so the next day I said I wanted out…it seemed to kind of, not frighten me in some way but, it felt like there was a ghost. It kind of made me feel spooky. I was concerned about just walking in the bedroom and the bathroom and there's something always following me…And I still don't understand why because I knew about the program. I just don't understand why I felt that way until I actually had it installed.

This resident apologized repeatedly for not appreciating how the system would affect her before having tried it. Like others who discontinued, she was aware that the housing organizing paid $200 for installation and felt guilty, but insisted on having the system removed.

Residents experienced discomfort with the system for a variety of reasons. One social worker explained, "We are very sensitive about providing this service to survivors or people who have some kind of paranoia because the light flashes so some people are uncomfortable with it. I think one client, she is a Jewish client, got it installed and then got it removed because 'it's too many sensors and I'm not comfortable.'" Few residents with a diagnosis of dementia in these independent living residences had ever used the system, but some discontinued because it caused confusion. For residents who did not speak English, having the telecare operator call in response to a signal and greet them with English was troubling, despite the procedure in place to dial in a language line after the initial contact was made. One resident described how being in an emergency, afraid, and possibly in shock could make one sensitive to incomprehensible words projected through the device.

Another common reason cited for discontinuation as well as nonuse was the fear of EMS being called when a resident was not home, or for a nonemergency. This had occurred more than once in these residences. One resident's traumatic experience of having their door broken in was another resident's cautionary tale against adoption. A social worker described the response of nonusers who witnessed an EMS visit when their neighbor was not home: "The fire department broke a door and you're [resident] responsible for repair. Look at me, I'm fine without it. It's your stupid choice and it just ruined your door." A discontinued user who was visibly emotionally distraught while recalling the incident that occurred over a year prior, reflected on this experience of public embarrassment. She had come home to a broken door and no one but a neighbor present to tell her about the dramatic scene surrounding her vulnerability that had occurred in her absence. She discontinued the system immediately after and has refused any form of alert system since. Users of passive monitoring were unconcerned about the possibility that the sensors in their apartments would be stigmatizing, but the EMS visits were significant events that generated shame and blame.

Creative Misuse and Unmet Need

Current users of the passive monitoring system sometimes manipulated it to their own ends. Desire for control over fall response and relieving social isolation are described here.

Unmet need: control over fall response. Falls were common occurrences for some residents. Having control over the response to a fall was important to residents, not only to avoid unnecessary inconvenience, but because they viewed a day spent in the ER as a waste of time. Social workers participated in this negotiation when residents resisted calls to EMS, such as when the passive monitoring system triggered an alert and they were the only ones available to check on the resident. Generally, this involved communication with the family members to confirm that these wishes should be respected. An 82-year-old woman described with a glint of mischief in her eye how she outsmarted the passive monitoring system to avoid troubling her busy daughter or wasting time in the hospital:

I fell and was on the floor for half an hour. I just scooted across my apartment over to the phone and I called up my neighbor and he came and picked me up. I scooted over to the front door to open it. I don't know if it's true, but if I call the super he will not pick

me up. He will call the hospital. The ambulance would come but I don't like to go to the hospital because there's nothing wrong with me and if it's not serious they make you wait for a long time for hours…I did not press the button because I could just move across the floor so the sensors would not know that there is no movement. That's what I think. I just scooted scooted scooted just sitting on the floor. So that's why the system doesn't know.

She spoke with pride as she recalled maneuvering to obtain the desired response to her fall.

Some residents described difficult situations when policy prevented a response in line with their actual needs; others directly critiqued the policies. An 81-year-old current user made the following observation:

There's nobody in this building at night to pick you up if you fall. No super. I can't have home care because I have a pension. So how can I call 911? I needed a way. I saw people fall down and need help. But the home aide can't pick them up, super can't, and I tried and could not. They have to call 911 – how do you do that if you don't speak English? This building is not for seniors.

This resident cited the higher incidence of falls when residents get up at night to use the toilet and are not fully alert. It did not make sense, in her view, that no one was available in the building to help people during these riskier hours.

Response management was not enabled by the monitoring system, which triggered a series of automatic processes in response to alerts generated by algorithms. Residents wanted control over these processes to avoid wasting time with unnecessary hospital care and troubling their emergency contacts.

Unmet need: Social isolation. The majority of residents directed their interview to the topic of unmet social need for interaction and described intense and persistent feelings of loneliness. Many identified the problem of being physically separated from their former communities because their neighborhoods lacked affordable and accessible senior housing. Transportation, while available, felt inaccessible and required long and sometimes uncomfortable wait times with no guarantee that drivers would follow the ride plan. One 94-year-old passive monitoring user described the cabbage roll parties she had hosted over decades for which local friends would gather at her home. Since being moved to the independent living residence in a distant borough ten years earlier because her borough lacked accessible housing, she has not seen one of those lifelong friends. This problem was common among the study's participants.

Social workers were aware of the severity of the issue of social isolation. When asked to name their biggest concern for the residents, they focused on residents' mental emotional health. One elaborated:

My major concern is that they stay in their apartment thinking and thinking and thinking without coming out and socializing and then they become depressed and depression is associated with many other chronic disease…This is my biggest concern, that's why I would like to have some program which they will feel fun and relaxed, no burden, not exercise, not education, not presentation, but just fun and I have noticed a few times while they are waiting I click on the TV and let them sing, they are so happy….I actually don't worry sometimes too much about their physical health because they have a doctor. Is it is the mental emotional that I worry the most and usually most of the time that causes the trouble.

While the passive monitoring system left little room for resident control (no pause button, no mutual information shared about caregivers), need for social interaction was so pressing that some residents manipulated telecare calls into social calls. One user's alert records over the past 12 months indicated that 45 of the 53 incidents were caused by reaching the hot temperature threshold. The telecare operator had typed on 30 occasions, "Please contact in regards to possible reprogramming." When social workers asked this resident if they could adjust the threshold for her to make it as hot as she liked it, she replied that she did not want the telecare operators to stop calling because she enjoyed having someone call regularly to ask how she was doing. While social workers allowed this to continue for many months, this was a temporary solution to this resident's problem, and only available to English-speaking users because the language line would not accommodate small talk.

Other residents were less successful at getting their need for social interaction met through manipulation of the technology. A resident with mild dementia was unable to influence the number of social calls she received from the telecare center and expressed a high level of irritation over this. With a raised voice, she complained: "they don't call me anymore! I want them to call me, 'how are you? What are you up to?' They don't call me anymore, I want them to call me. It just beeps beeps beeps!" In addition to dementia and physical isolation, hearing loss without access to an appropriate hearing aid was a common barrier to staving off loneliness. This was the primary problem for one 65-year-old man who used a wheelchair. He decided to discontinue the passive monitoring system because he could not hear the telecare operator. The reliance of the system on one's ability to communicate with the operator made the system completely useless, as he put it, but his need for assistance in an emergency paled in comparison to his need for social interaction:

> The most important thing is the ear, and since I cannot understand, it's the most uncomfortable. You have no idea—basically there's zero communication with sounds. Because I'm hard of hearing. I wouldn't know what others are saying and I cannot comprehend, so it comes to a minus. And even if I want to very badly, I just can't. Because I can't hear. This is the most—handicap that I have…I can't go to social gatherings, and I can't go to church.

Like other former and current users, this resident could not configure the passive monitoring system to meet his most pressing needs. Some actively complained while others asked the social workers to discontinue their subscriptions.

DISCUSSION

The spectrum of resistance described here challenges the dominant image of passive subjects of passive monitoring. The counter-strategies older adults employ would indicate that *passive* monitoring may be a misnomer, but what are they countering, responding to, and resisting? From the woman who scooted across the floor to avoid sensed inactivity to the man who discontinued because it was useless to him despite the social worker's insistence, these residents, in unique and sometimes creative ways, resisted the expectations of regularity of routine and passivity built in to the technological tool. This is remarkable in light of the fact that the technology provided little room for resistance or creative use; it was designed to be passively received with minimal added burden of learning how to interact with it. Residents subverted an implied identity, continued negotiating their own needs after adopting the system – sometimes

through the system, sometimes by refusing the system – and they saw through the rhetoric and marketing terms of "passive monitoring to promote independence" ("a person who is independent may not want it"). Most often, they resisted it by saying no and holding firm to that decision.

The co-production of old age and passive monitoring technology can be seen in the ways older adults interact with the intervention. Passive monitoring is shown to be "a source and consequence" (Wajcom, 2010, p. 149) of age relations – a relationship exposed in the disconnect between need and product, as well as the clash between identity of the subject and the technology and accompanying script designed for the subject. Technology and age relations are intertwined and mutually shaping. The "rational" solutions developed by engineers and designers who are predominantly young, able-bodied and male are situated in a context of age and gender relations where expectations and assumptions about users are embedded in technological solutions for them. The findings presented here indicate that these relationships are not neutral, nor is the marginalization of older adults in technology development and service design spaces. Certainly, political and economic contexts affect whose priorities prevail and how problems are defined. The power to interpret needs and develop technological solutions can be viewed in contrast to the residents' effortful integration and discontinuation of the passive monitoring system. The study of diverse forms of use and nonuse reveal ways in which the priorities of users (e.g., safety, privacy, control, contact) are not comfortably traded and are more diverse and multi-faceted than those of the housing organization and family members (e.g., safety, efficiency).

The passive monitoring system and its users exist within a larger context. While the passive monitoring system privileges the need for individual safety, other needs and practices reflect gaps in broader systems – limitations of existing LTSS models, policies which limit available resources for senior housing in neighborhoods where seniors live, liability issues which mitigate against giving someone a hand to stand up after they have fallen, and social exclusion. These problems and needs are so real that residents are rejecting or creatively manipulating the intervention they have been offered to attempt to meet them. A timely question would be how can technology be refocused to ameliorate these power differentials that order whose priorities are represented? We might start by interrogating the dismissive stance that nonuse is "irrational" and that unintended use is "misuse."

CONCLUSION

Responsibility towards users requires attentiveness to the neglected nuances of use and nonuse on their own terms. Older adults are not, in fact, passive recipients of passive monitoring. When nonuse, creative use and other forms of resistance to technology are examined, we discover how passive monitoring and the reductive understandings of need upon which it is built do not often deliver desired benefits. The study of nonuse, discontinuation and unintended use helps push beyond the notion of noncompliance and generational incompetency and into the generative study of the meaningful, motivated, and active qualities of older adults' decisions and negotiations.

Paper 2: Breathing room in monitored space: Opportunities for privacy in boundary management

INTRODUCTION

The technological generational shift from active personal emergency response systems to passive continuous monitoring installed in the living space of older adults has raised concerns about the invasion of privacy (EFORTT, 2011; Huber et al., 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 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?

Most of the literature in which privacy and personal health monitoring are discussed (e.g., 'ambient assisted living', 'smart home', 'assistive technologies') focus on 'information privacy;' that is, aspects related to one's own control and dissemination of personal data (Mittelstadt, Fairweather, McBride, & Shaw, 2013). Personal privacy – unamenable to data security enhancement solutions – receives inadequate treatment and is often framed as a hurdle to acceptance rather than a normative concept (Mittelstadt, et al., 2013).

Townsend and colleagues (2011) conducted a review of the literature on older adults' attitudes about and perceptions of home monitoring sensor technologies and conclude that older adults will trade privacy for autonomy. The idea that continuous home monitoring can be perceived as protecting one's privacy has also been raised in multiple studies, in terms of trading some privacy loss for greater privacy loss in alternative residential settings (McLean, 2011; Essén, 2008; Huber et al., 2011). Researchers have also highlighted the subjective nature and diversity of experiences of privacy with passive monitoring (Hensel, Demiris and Courtney, 2006; Huber et al., 2011). Differences between older adults and family members with regard to perception of need and comfort with various levels of data granularity can be expected (Huber et al., 2011). In one study, older adults confirmed that they felt that their perception of need would supersede any privacy concerns, yet very few thought passive monitoring technology would be needed despite their advanced chronic conditions and physical limitations (Courtney, Demiris, Rantz, & *Skubic, 2008).* This work names not only a tension between values, but a tradeoff, while others describe it in more dynamic terms of striking a balance.

It may go without saying that full knowledge and comprehension of monitoring data collection and sharing is required for one to be able to reflect on how it violates or protects one's privacy, yet older adults may have difficulty understanding what data are collected and how they are accessed. In a study of privacy and information technology, older adult focus group participants had "naïve mental models" about information privacy, difficulty understanding what data were, why they would be collected, how they would be stored, shared and accessed (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). This is significant because designers and engineers will struggle to integrate privacy options into their products if terms of privacy are not worked out. The disconnect between privacy theory and applied research and

product development (Mittelstadt et al., 2013) may prevent the development of passive monitoring technologies that meet the privacy needs of older adults.

The Meaning of Privacy Today: 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 (though anonymity can no longer be assumed in public space) (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, Demiris & Courtney, 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 practices. Privacy – like risk management – is an evolving value. In the literature on passive monitoring, authors most commonly frame it as a trade-off: autonomy v. privacy or independence or safety v. privacy. 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 it cannot be enjoyed by everyone; those in need of support or care must exchange their privacy. Given the creative possibilities and achievements of technological innovation, I question whether this simplistic exchange theory should be accepted. Can technology do no better to preserve or enable privacy? The same questions might be put to gerontologists and privacy scholars. Innovation may be constrained by the slow-to-evolve ways in which we conceptualize privacy, its role and significance.

In order to develop generative ways of thinking about privacy, it helps to understand what is at stake. The question of how passive monitoring impacts older adults' ability to keep personal matters to themselves and prevent experiences of private-life intrusions is important because privacy is not only about physical space or the nature of accessed information, but it is also about subjectivity. Legal scholar Julie 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 multi-country study of technology for older adults, users of personal emergency response systems (PERS) 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 thus far, namely, the significant role of interpersonal relationships in older adults' lives as well as the evolving subjectivities and diversity of concerns they have expressed.

In this paper, I present findings from a study of the lived experiences of older adult residents of subsidized independent living residences, family caregivers and residence staff with a passive monitoring system intended to help predict and respond to emergencies and health events. Sensor-based monitoring collects data on movement activity for remote access display and uses algorithms to trigger automatic urgent and non-urgent signals. Telecare center operators respond to possible emergencies with a call to the resident, followed by emergency contact, and depending on the nature of the alert, EMS. Sensors were located on the bathroom doorway, in the bathroom, in the refrigerator, and above bedroom and apartment doors. Activity that deviates from what the system "learns" in the first few weeks of use is normal for an individual is recorded and emergency contacts are alerted through daily e-mails and a web-based interface that displays activity level by hour. I will present analyses of interview data against the backdrop of new conceptualizations of privacy in a digital age.

METHODS

Data were gathered using in-depth semi-structured interviews in English and Korean with elder residents, family members and technology and social work staff of six urban low-income independent living residence apartment buildings. The buildings are owned and operated by a senior service organization that had offered residents the option of adopting a sensor-based remote monitoring system for six years. The system consisted of five sensors installed in specific locations within their apartments. Adopters were required to have two emergency contacts willing to respond to alerts generated by the system's telecare center. The housing organization fully subsidized installation (~$200) and monthly fees for the system (~$85); residents paid between $5 and $25 per month for the service. For a detailed description of the methods, see the Methods section of the Introduction.

Participants

A total of 47 interviews were conducted with 41 participants: 15 current user residents; five discontinued residents; 11 emergency contacts; and ten staff members. Fifteen of the 23 current users in the six buildings were invited to be interviewed and each agreed. Five of eight residents who had discontinued within the past year were interviewed; three declined to participate. Participating residents' average age was 87 (65-103). More than half (12) had a home aide and four had round-the-clock care with overnight aides. Each resident had multiple chronic conditions. Eleven emergency contacts were interviewed. Emergency contacts included daughters, sons, a granddaughter, sister and a home aide. All ten technology, housing and social work staff participated.

The semi-structured interviews were conducted in person with the exception of five interviews with family members conducted 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.

Privacy was addressed directly and indirectly during the interviews. It was discussed when staff described their procedures for following up on urgent and non-urgent signals and data collected by the system, as well as concerns residents had expressed and how they weighed these concerns against the system's potential benefits. Staff, residents and family members were asked directly if the passive monitoring system had any impact on privacy. The decision to bring up the

word privacy rather than allow it to emerge organically was made so that each participant would have the opportunity to speak directly to it. The questions were addressed in interviews with all participant groups to understand multiple perspectives on the same issues.

Open and closed coding were used to analyze the data in an evolving process as it was collected (Glaser & Strauss, 1967; Corbin & Strauss, 2008). Closed coding allowed for identification of excerpts where participants answered specific questions about "privacy." Open codes were derived from the data and were modified throughout this process; corresponding memos were filed by these codes. Axial coding was used to reassemble the data and relate concepts to each other to produce an explanation of the situation (Corbin & Strauss, 2008). After generating a list of themes, all data were reread and instances of evidence consistent or inconsistent with the themes that emerged were noted.

FINDINGS

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 informed consent to install it. 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.

Figure 1. Screenshot of a daily e-mail generated by the passive monitoring system for emergency contacts and staff.

Activity	Current Status	
AM Bedroom Exit	J. Doe woke up this morning and moved around the home.	View detail
Possible Bathroom Fall	Green: No suspected bathroom falls were detected.	View detail
Meal Preparation	Green: Meal preparation was in the normal range.	View detail
Activity Index	Green: Active in the normal range over the past 24 hours.	View detail
Night-Time Bathroom Visits	Green: 10 Bathroom visits; usage in the normal range.	View detail
Motion Through Door	7 Motion Through Door events. This data could represent activity by a client, staff, or visitor.	View detail
Room Temperature	Yellow: Room Temperature was sometimes slightly higher than recommended. Call J. Doe at home and ask them about this condition.	View detail

Residents each had two emergency contacts who could respond to telecare center alerts as first responders. The telecare center responded to six possible conditions divided into four "urgent red signals" and two "non-urgent red signals." Urgent red signals triggered when the sensor-based algorithms indicate that there is 1) a possible bathroom fall; 2) no bedroom exit; 3) the ambient temperature is above or below the set threshold, or 4) no base station dial-in (the system was based on operation of a phone line; base station would not dial-in if the phone was off the hook or the line was momentarily down). Non-urgent red signals indicate 1) significant

low level of overall activity or 2) significant change in nighttime bathroom use. As seen in Figure 1, information beyond the red signal data was available to emergency contacts and social workers. Additional information included change in meal preparation based on a sensor inside the refrigerator, number of times there was motion through the apartment door, and actual number of nighttime bathroom visits.

When an urgent or non-urgent red signal was sent, the telecare center operator first phones the resident, then the emergency contact(s). If the resident and emergency contacts are unreachable, the operator leaves messages for the emergency contact and continues to call every 60 minutes during waking hours except in the case of a possible bathroom fall, for which EMS is called. After the situation is resolved, the telecare operator summarizes the event in notes that are emailed to the social work and technology staff. Social workers were expected to follow-up on telecare center calls with a phone call to residents after the situation had been resolved.

Social workers describe their follow up conversations with residents as an individualized process in which they drew on their knowledgeable about the health and family conditions of each, as well as residents' feelings about having the passive monitoring system. The social worker who had the most clients who used the system described her procedure of asking three questions during her follow-up calls. She explains, "even though the client said 'oh, I'm fine, somebody called me already,' I still have to go through three questions." These questions are not set by the organization; each social worker develops their own procedure for how to check in with their clients. This social worker described her checklist of follow-up questions: "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 justifies this line of questioning as enabling her to obtain the information she should know in order to use the system for prevention. The telecare center "just wants to make sure they are fine and no help is needed…But there is something behind [it] and need for a social worker to explore because the call center will not explore this part." 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. Even though the call center called them and said everything is okay then we still have to understand." 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

The close examination of actual procedures and practices of passive monitoring use is important to understand when we consider how the system impacts privacy. Privacy is highlighted in this passive monitoring system company's marketing materials and in the housing organization's flyers placed throughout the residence buildings. The technology company's 2013 promotional video for senior housing organization administrators introduces the concept with this voiceover: "Today a new generation of smart systems is poised to revolutionize the way senior communities deliver care to their residents." Soon after, the voice says "Residents

continue to go about their normal routine with their privacy intact." The video goes on to describe its function as follows: "detect daily activity of residents…which could indicate something clinically significant, such as a UTI. Alerts can help enable quick intervention." 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 [system name] provides, staff can proactively intervene to safeguard residents." (system website video, 2013). The marketing video brushes over questions about privacy with the simple statement, "with privacy intact." The senior housing organization follows suit. In the flyer created by the organization and translated into four languages, titled "Do you worry about falling and no one knowing?" there are four eye-catching bulleted benefits, two of which read "Helps you maintain your independence and privacy" and "Is virtually invisible." Concern over privacy intrusion is anticipated and dismissed by the providing organization and the company that provides the passive monitoring system.

Among those considered appropriate potential users, social workers reported an average rate of adoption at 2%. Among the reasons cited for low uptake was that it would be intrusive or violate privacy. Some who did adopt discontinued after experiencing it because they found it uncomfortable to be tracked and have the housing organization staff aware of their movements. 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. If privacy is said to be kept intact, what does privacy mean? What is the implicit gain that diminishes concerns over privacy? What is it about the target population that enables a company and non-profit senior housing provider to assert that resident privacy will be maintained with the introduction of a system that tracks movement activities in the home? Below, I present the ways in which privacy is articulated by staff and residents who navigated and adjusted their practices around concerns raised about passive monitoring.

Privacy Articulations in Practice

The breakdown of residents' general responses to questions about how the system impacted their privacy was predictable: those who did not adopt the technology (the vast majority) or who discontinued it felt it was intrusive and a threat to their privacy, while residents who adopted it 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 who were identified as appropriate potential users to decline the technology was concern over privacy. In the words of one social worker, "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 described 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." Social workers confirmed that privacy concerns lead to non-adoption, even in situations when need appears high. A resident who had fallen in the bathroom and had 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." Reflecting on non-adoption, another social worker explained that residents "would like to come up with a certain time they are completely by themselves. They don't want anything, they don't want anything or anybody helping them." When residents imagined their privacy would be violated by the use of passive monitoring, social workers could not convince them to adopt.

A number of residents had an additional concern that the system was actually a camera. Social workers referred to them as "paranoid people." The flip side of this barrier to adoption is a second articulation of privacy.

Privacy is intact if they can't see me. Nearly all current users reported that passive monitoring does not negatively impact their privacy because it does not involve a camera ("I was thinking on it but they cannot see you naked"). Family members serving as emergency contacts agreed that there was no intrusion of privacy because "they can't see anything." Some residents responded to the question with a request for confirmation: "No, it's only motion…right?" The idea that privacy was not an issue because the system did not provide visual images of their bodies or movements – that it was not a camera – was the most common response from current users and family members.

Privacy is intact if alternatives are less private. Social workers and a couple resident users 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: "I know a lot of people, Russian speaking, Chinese speaking, they understand that they need help but they can't tolerate sometimes another person in their apartment. That's what passive monitoring is for, the people who don't tolerate the human being [laughs]. 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. I thought it'd be helpful if I had such situations." Another woman with a home aide eight hours 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!

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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 made up excuses to check 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. Another woman was hot in her apartment all the time. I said to her 'Is it true that older people like it hot?' I did not ask her directly because I knew her temperature was high and was getting alerts. She said 'I hate the heat - you know how many times I've asked the super to open the window and he's not responding?' So I called the super to fix it. I think this little thing if used properly could help a lot.

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 – "I tell her you always look so beautiful and you look pale, are you sleeping well?" – social workers reported that some residents appreciated their concern and were willing to talk to them about their situations. 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 healthy 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 QC, 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.'" Here, 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 in the moment of follow-up (i.e., "I'm calling because it appears you were restless last night") 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 users' alert records. One-third of the residents were unable to consent because they did not comprehend that information could be accessed about them. I also made contact with emergency contacts with the consent of residents. One woman who was very 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 he 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 – though the telecare center remained a mysterious place – but the prevention component that involves the tracking by hour of activity and designation of normal and nonnormal ranges of activity were not clearly understood. Social workers tried showing clients on their computers: "One woman who's really sharp but just doesn't understand it. I show her on the computer and she's like 'I really don't get it.'" Another 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 their clients.

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 (Mortensen, Woolrych, & Sixsmith, 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, such as inability to sleep due to distress over arguments with adult children, with some ambivalence. They discovered a variety of things, such as pets whose fees were not being paid and the practice of washing undergarments in the bathroom. A social worker described a recent 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 just the word privacy…I think it's more toward a kind of counter-answer to the question that a client might have, "is it private?" I don't see it as keeping it very private because you know the social workers know what's going on in your life and the first responders know what's going on in your life so I don't know if that's what they mean. It's, because it's marketing...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 a possible bathroom fall alert:

> 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 or not the resident was told what was learned about them that motivated the intervention.

These practices of following up on data that sometimes lead to incidental findings could be disconcerting in residences where staff prioritize policy without the preferences and welfare of the residents in mind. For example, at this mission-based non-profit, social workers assured potential users that passive monitoring could not interfere with their tenancy because fair housing is in effect. One supervisor told residents "If you fall 15 times we're not going to put you in a nursing home." She explains, "because sometimes they have questions, 'so now you're going to know more about me.' I think less than 5% of people have that concern." In practice, this non-profit was true to this promise. For example, after a social worker discovered through high bathroom activity notifications that a recently unemployed daughter had moved in with a resident, she did not record it or attempt to have the daughter kicked out. Without revealing why she was inquiring, the social worker was able to pull the information about her new roommate from the resident and made an informational intervention: "I don't think I did wrong but I gave food stamp and staffing agency information. I did an extra step. I was thinking ahead about the daughter being a burden on my clients. I did it in a tactful way." Here, privacy is not invaded, according to the social workers, because they do not know why they are being questioned.

"Yes But No": Ambivalent Perspectives on Privacy

Not all social workers felt unequivocally that this constituted good practice. One in particular disliked the fact that incidental findings led to interventions. She worried that it bordered on ageism: "Some people make bad decisions and bring the wrong people into their lives and just because they are seniors they can't do that – I don't think that's right." While social workers were told to start their days by logging into the system to check activity level signals, this worker refused: "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 you get up so early?' 'why 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 and tell her they have a situation like diarrhea: "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. It really depends on how the person looks at what they are doing, like washing clothes because it is urgent and they cannot make it because they have diarrhea. Some people would think I don't want that but some people think it's not a big deal so I would still say yes, yes. Because, yes [privacy is intact]." Later, she noted that it is her relationship with residents that protects their privacy:

> That's why it is very important when we see there is an alert the call center says okay no help needed we still call because I know there might be something else but they do not want to share with stranger will tell us. In a sense yes, privacy is intruded [laughs]. 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 sometimes some think they would rather tell us then 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 doesn't bother her: "My son knows me. My children think it's good for me." All social workers recognized the importance of not having to disclose information to the telecare center operator, for example, after a fall a resident may tell the operator nothing happened if they are not in need of help. A social worker explained: "Usually they tell you it's a victory – 'I managed it' to someone they know but don't need to disclose the details to strangers at the call center."

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 10 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 naked and alone (the interviewer did not use the words "sexual" or "partner" to qualify intimacy because she wrongly assumed it was implied). Social workers replied that because it was not a camera, residents could not be seen getting dressed and therefore were not concerned about intimacy. 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.' 'Why were you in the bedroom for four extra hours?' 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, while 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 older adults preferred it this way.

DISCUSSION

Residents and social workers did not employ a static articulation of privacy. Their diverse articulations included: monitoring movements in the home is a violation of privacy; privacy is intact if they cannot see me; 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 boundary management framework suggested by Cohen (2012), which draws attention to the question of how the introduction of passive monitoring changes boundaries and tools for managing them.

This passive monitoring system produced new knowledge about residents and enabled social workers and family members to decide how much of that knowledge to disclose. They chose not to disclose at times for one of two reasons or a combination: They had reason to believe the individual may not want to be subjected to this knowledge and recognized that unanticipated feelings of privacy invasion may arise, and they understood that some resident users – in accordance with previous research findings – do not comprehend the extent of its features. This passive monitoring system was complex and difficult to explain. Without full information about 1) precisely what information is collected and how it is accessed by whom, and 2) knowledge of when it is being used, residents are under the illusion that their privacy is secure behind a set of boundaries they believe they control. A significant minority of users could not consent to have a researcher access their alert records because they lacked knowledge about the collection of information about them. Social workers agreed that privacy would be violated if the use of passive monitoring were not voluntary. Presumably, there should be a strong relationship between informed consent and voluntary use.

Social workers also compared residents' comfort level disclosing personal information to a stranger, a telecare center operator, with their comfort level disclosing it to them. They recognized that residents managed boundaries with telecare center operators by limiting what they disclosed by phone. Operators would not probe because they needed only to determine immediate need for emergency response, but residents were held accountable for their movements and activities in their homes by three parties: first the operator, then family members and social workers who ask probing questions and push for a satisfying explanation. Power to manage boundaries was diminished through passive monitoring use because residents had to answer for activity that fell outside their normal range, 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 the residents by knowing what the system is designed to tell them. This indicates that privacy was at issue, but social workers' efforts to protect privacy and maintain resident satisfaction with the system undermined residents' ability to manage their own boundaries.

The passive monitoring product's marketing materials claim that this new knowledge empowers staff. At these independent living residences, social workers were individually responsible for negotiating how to follow-up with residents, and some took pride in the ways in which they leveraged it as tool for detecting unknown issues. In these ways, passive monitoring was experienced as empowering – it did enhance their power-knowledge over residents. Social workers came to know intimate details that residents were reluctant to share with their own family members, yet not all wanted their relationships with clients impacted in this way. Social workers saw diversity among their clients and struggled to convince them not to be concerned

about privacy, attempting to manage multiple different boundaries for each of their clients without overstepping. This was not always met with success in part because social workers were not fully aware of the privacy needs of each. Some social workers reflexively recognized that their own perceptions of appropriate boundaries should not be the final word: "I have to think if they have a point [about privacy]…I have to educate myself too." One rejected the role altogether and called the practice inappropriate. For staff, negotiating and managing boundaries on behalf of residents was a mixed bag.

These findings show need for products and systems that are streamlined to ease understanding about what they do, along with clear organizational policy with respect to tightened informed consent guidelines and requirements to report system use to residents during follow-up. System comprehension and appreciation for what will be involved in use could be pre-tested in the lab with older adults before the product is put on the market. Organizational policy that requires staff to reveal to residents the source of their information may also relieve staff from negotiating privacy terms on their own. Room for residents to request that they not be informed upfront during follow-up could be reserved for those who have that preference. Other ways to personalize respect for privacy include collectively developed follow-up questions for each resident, perhaps during adoption. Social workers could use standard or personalized reminders for residents that they do not have to provide full information during follow-up calls, such as giving them an out ("I want to respect your privacy…"). Of course, success depends on staffs' buy in to the importance of these boundary management tools. Educational tools like role playing may be effective, though uneven implementation across providers should be expected.

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? This study did not measure understanding systematically enough to make robust comparisons and did not include nonusers. Moreover, if older adults who want the technology say they don't understand and they don't care to, are privacy concerns still relevant? These issues might be explored in future research.

LIMITATIONS

Residents who were offered the passive monitoring system and refused it were not interviewed. Data presented here were gathered from interviews with social workers, family members and current users and those who discontinued use. Learning about privacy articulations directly from those who did not want the system, possibly because of privacy concerns, would have strengthened this research. This study examined privacy articulations of residents and staff of independent living residences and articulations of privacy may differ in assisted living. Finally, social workers clearly felt social pressure to report positive things about the technology, partly because the selling of it and use was under their purview. Evidence of this includes a supervisor's false claim that no residents had discontinued the system for reasons other than a move or death. Still, social workers became more candid over the course of the six-month fieldwork and provided frank responses.

CONCLUSION

In practice, older adults and social workers express diverse approaches to privacy. If privacy is about subjectivity because "claims of privacy invasion are claims about unwanted subjection to the knowledge or power of others," then it is important that boundaries are 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 will be able to appreciate what it means to be monitored in this fashion. When social workers fail to disclose this information because they do not want the resident to make the connection between the technology and embarrassment or feelings that their privacy has been violated, they are disallowing breathing space for the resident to determine where their boundaries lie and how and when to negotiate changes. Given the diversity of privacy articulations and concerns, opportunity for boundary management might be employed as both a design and practice principle.

Paper 3: Calculating risk and the management of living: Social workers in a bind

INTRODUCTION

We live in a "risk society" (Beck, 2006) where risk is a defining discourse within which social work knowledge and practice are deeply embedded (Powell, Wahidin, & Zinn, 2007). Two interrelated concepts that represent for policy makers and practitioners the gold standard of aging today – 'aging in place' and independent living – are inherently grounded in concerns about risk avoidance (e.g., avoiding dependency and institutional placement) (Katz & Marshall, 2004; Vasunilashorn, Steinman, Liebig, & Pynoos, 2012; Wahl, Iwarsson, & Oswald, 2012). Over the past two decades, technology has increasingly been featured in the literature on aging in place (Vasunilashorn, Steinman, Liebig, & Pynoos, 2012) in terms of its potential role in enabling independent living and mitigating risk of dependency. Writing about passive monitoring technology, Wild and colleagues (2008) assert that "For older adults to remain at home, methods to detect cognitive and physical decline that put them at risk must be in place" (p. 182). This sentiment that living at home is risky for older individuals and that calculating risk of decline will shore up one's independence is widely assumed in the literature on technology for independent living.

Sensor-based passive monitoring systems that enable remote monitoring of location and movement behaviors in the home are designed through the lens of risk for a risky population. In advanced liberal societies, the elder subject is said to pose a risk to the larger population as a dependent and costly public resource drain. Social gerontologists have illustrated how individuals are encouraged to be concerned about their cognitive health and well-being and to take responsibility for calculating and mitigating the risk they present to the larger population (Williams, Katz & Higgs, 2012). Indeed, the language of apocalyptic gerontology that problematizes the anticipated catastrophic impact of a dependent population (e.g. the 'demographic crisis' and 'silver tsunami') is widely used by technology researchers (Sixsmith & Gutman, 2013).

Strategies for identifying *individuals* deemed most at risk are increasingly common, coupled with intervention strategies in the name of prevention (Rose, 2006). Rose (2006) writes that risk refers to "a family of ways of thinking and acting that involve calculations about probable futures in the present followed by interventions into the present in order to control that potential future" (p. 70). The promise of being able to control the future by making risk knowable is a primary justification for using passive monitoring technology to monitor behavioral bio-markers of older adults. The "individualization of risk" (Rose, 1999, p. 269) is evident in the discourse and practices of passive monitoring technology, in which the problematization of population aging is fixed to the subjectivity of the individual.

The extant literature on passive monitoring suggests that risk's relationship to independence is worth exploring in the context of this emerging practice. Passive monitoring is described as a tool to enhance independence through earlier detection of possible health events that might trigger a move to a more restrictive living environment, yet older adults and caregivers have also expressed concerns about remote monitoring undermining independence, self-determination and choice (Percival & Hanson, 2006). Focus group and pilot study participants have expressed concern that remote monitoring will reduce privacy, act as "big brother," or undermine elders' power to keep information about themselves private for their own

reasons (Mahoney, Mutschler, Tarlow, & Liss, 2008; Percival & Hanson, 2006). Even caregivers who might be adversely affected by daily risks faced by their family members stated that older adults "have a right to 'take the risk of living the way [they] want to'" (Percival & Hanson, 2006, p. 895). Participants felt that the technology would become like "big brother" if that right were eroded or if people were pressured to use it (Percival & Hanson, 2006). The actual practices of offering the intervention and the decision making processes in which these issues would take shape have not yet been explored.

This project sheds light on the practices and rationalities formed around the selling of a remote monitoring technology to residents of service-enriched subsidized senior housing. This study reveals how social workers navigate the task of encouraging an extremely reluctant independent living population to subject themselves to continuous monitoring in their apartments. Having to navigate this sociotechnical practice puts social workers in a bind, caught between values of independence and risk management and an intervention that the vast majority of residents for whom the intervention is deemed appropriate independently reject.

METHODS

Data were gathered using in-depth semi-structured interviews with elder residents, family members and technology and social work staff working at six urban low-income independent living residence apartment buildings. The buildings were owned and operated by a senior service organization that offered residents the option of adopting a sensor-based remote monitoring system. The system consisted of five sensors installed in specific locations within their apartments. Adopters were required to have two emergency contacts willing to respond to alerts generated by the system's telecare center. Social workers and technology staff received summaries of alert responses and daily e-mails about the residents' activity levels. For a detailed description of the methods, see the Methods section of the Introduction.

A total of 47 interviews were conducted with 41 participants: 15 current user residents; five discontinued users; 11 emergency contacts; and ten staff members. Out of a total of 41 participants, the majority (33) were women, and half (22) were foreign born. Participating residents were age 65 to 103 with an average age of 87.

All technology, housing and social work staff participated. The ten staff members included three US- and seven foreign-born participants. All social work staff were women (6) and all housing and technology staff were men (4). Staff were recruited to participate during a routine meeting where they were invited to contact the researcher if interested. Each agreed to participate. The semi-structured interviews with staff were conducted in their private offices with closed doors. Interviews addressed a range of questions, including processes of decision making about adoption and social workers' specific procedures for offering and using the technology.

The grounded theory method was used to analyze the data in an evolving process as it was collected (Glaser & Strauss, 1967; Corbin & Strauss, 2008). The transcribed interviews and memos were analyzed for concepts and possible themes using open coding into Dodoose. Codes were derived from the data and were modified throughout this process; corresponding memos were filed by these codes. Axial coding was used to reassemble the data and relate concepts to each other to produce an explanation of the situation (Corbin & Strauss, 2008). After generating a list of themes, all interviews were reread and instances of evidence consistent or inconsistent with the themes that emerged were noted.

The Remote Monitoring System as Intervention

For the past six years, the current study's field site has made sensor-based remote monitoring technology available to residents on a voluntary basis. This sensor-based system monitors ways of moving and living in one's home, patterns and level of activity, length of time spent in the bathroom, time bedroom is exited in the morning, number of times the refrigerator is open and bathroom is used at night, and the coming and going from the apartment. It is a two-pronged intervention that enables both telecare response to signals deemed urgent, such as bathroom use for longer than 60 minutes, and preventative action in response to signals and information deemed nonurgent, such as change in nighttime bathroom visits or infrequent use of the refrigerator. The goal is to prolong independence by decreasing response time to a fall, detecting health events through the tracking of bio-behavioral markers, such as the association of frequency of bathroom use with urinary tract infections, and ultimately preventing or postponing relocation from an independent living residence to costly assisted living or a nursing home. Here, the concept of risk calculation is brought into the management of living conditions.

The risk calculation involved in remote monitoring involves a whole ensemble of practices and mechanisms that are important to overview in any discussion of adoption decision making. The decision to subject oneself to remote monitoring results in additional requirements, including responding to questions of the telecare operator, family and social workers ("Why did you use the bathroom more than usual last night?"). Additionally, an array of techniques are employed in remote monitoring, from the device itself to data analyses, data viewing on a regular basis, and the integration of that practice into care work by social workers and family members. While family members serve as emergency contacts and first responders, the social workers who work in each of the independent living residence buildings are responsible for viewing the daily email updates about each resident and following up on all alerts and telecare contacts with residents. They also receive the notes made by the telecare center operator about calls they made with each residents and are responsible for contacting residents who had an alert triggered to find out precisely what triggered the alert.

The most critical component in the use of remote monitoring is convincing residents to adopt the technology because this is what enables the practice. Social workers offered it to those who lived alone, were considered frail, had had an incident like a fall or seizure, had a change in their health or functional condition, or did not have enough aide hours. This described many of the residents, nearly half of whom had a home aide. In this independent living setting, residents were assured that their decision about using it would have no impact on the services they received.

Ambivalence under Organizational Pressure

The offer of the remote monitoring system was a part of a technology innovation program for which the organization enjoyed recognition from public and private partners and grant makers. It was not a direct fundraiser for the organization because it subsidized the hardware and monthly costs for its participating residents, yet because the organization was invested in the programs' success and employed a technology department, social workers were under pressure from their supervisors and the organization to "sell" the technology. The staffing hierarchy fell along racial and gendered lines: white men served as director and technology staff; the social work supervisory role was held by a white immigrant man who supervised a woman of color

who supervised five social workers, four of whom were immigrant women and one a white native-born woman.

Each social worker explained that at implementation six years prior, there were frequent meetings and a heavy emphasis on making the program successful by recruiting a sufficient number of users. Leadership dictated that the intervention be implemented and social workers were given an informal quota to aim for. One had joined the organization after implementation and recalled when the director (her supervisor's supervisor's supervisor) spoke with her about it: "[He] talked to me personally about [the technology]. I was told this is really important so be on top of this." The majority of the social work staff supported the use of the system as "another tool in [their] toolbox," though initial adjustment to the system and buy-in took time for most. Technology staff expressed disappointment that some of the social workers are less enthusiastic than others about the system and consequently (presumably) achieve lower adoption rates among their clients.

The decision of residents who were targeted as potential users to decline the system was described as "irrational thinking" by leadership who viewed the system as an opportunity to safeguard against known physical and health risks. Social workers expressed a more nuanced view; they were the ones who talked with residents about the technology and who residents confided in about why they did not want the system.

Some social workers felt restricted by the organizational pressure to express enthusiasm: "I'm frustrated because it's more about promoting this program. The reason people don't like it is what we need to know, to understand." This social worker continued: "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." Another described her ambivalence about the program being worth the effort:

> So much manpower we have to watch every day the e-mail for this and that. In my building I don't see any great rescue. But Jeff [technology administrator] gave me some examples, because sometimes I would lack of confidence, *why are we doing this*? I'm willing to try it but after I had been trying awhile, I also have to question myself: is this worth it or is this necessary? Then he gave me some examples and I said okay yes okay. I don't remember what example he gave me but for that kind of thrilling striking example, it didn't happen in my building, no.

Social workers agreed that despite their best efforts, the vast majority of residents resisted the technology. A social worker who reported that 98% of the residents offered the system directly say no added that "even getting that 2% is hard for social workers." Referring to the information meetings and high subsidy provided, another explained, "You need to consider how much effort [the organization] has put into getting it…I only have two users so it tells you something." Another noted, "Compared with the effort we put into it, people are not willing to take it." These efforts were significant because despite social workers' misgivings, promoting adoption was their responsibility; alternative actions were unviable under this pressure to sell.

Encouraging Adoption: Bypassing, Moralizing, Appealing to Fear, and Bargaining

Social workers justified the techniques they used to pressure residents to adopt by couching them in terms of supporting the organization's mission. Each emphasized the fact that the housing was independent living and that their goal was "to keep people independent as long as possible;" however, because residents made independent decisions to decline the technology,

social workers employed two divergent meanings of "independence": 1) resident control over decisions affecting their lives and 2) ability to remain in their independent living apartment. On the one hand, residents should be allowed to make their own decisions: "There are clients I think who should have it but have not agreed to it but it's their choice. It is independent living and they can make their own decision." This sentiment was echoed by a supervisor who explained what should happen when a client refuses the remote monitoring system: "If the client says no, it's no and that's the end. We don't talk to the daughter or the son or anything like…really I wouldn't say they're not allowed to per se, but it's not appropriate. It's independent living and it's not appropriate to make a call." The organization's expressed policy prioritizes the right to self-determination, defined as the freedom to make the choice and having that choice respected. Practice, on the other hand, favored another take on independence.

Bypassing the client. Most social workers did not practice according to the definition of independence as freedom to make one's own decisions because that led to nonadoption. As one noted, "Usually clients are resistant to it so it's important to not only talk to clients but to get the family involved." Another explained, "If the caregiver has a strong preference it's easier to adopt. It's about how the caregiver perceives [the technology] – if it makes their job easier. The caregiver usually decides about using it." A supervisor echoed this: "sometimes we bypass the client and talk to the family member, sometimes the family members are able to convince." Some social workers were very engaged in pushing for consent to install the system and described their strategies with a sense of pride:

> And then I encourage sure. You know how? I communicate with her daughter in [country outside the U.S.]. I have her e-mail and I explained to her that I'm concerned about her mother because she don't want to accept home aide, at least I will feel, *I* (points to self) feel more relaxed if she has [the technology]. The daughter encouraged the mother from [country outside the U.S.]. And then she said, "okay." She got it, yeah she [the resident] accepted. But I told you how difficult it was. [The resident would say] 'No I don't need this, later, later, later, later…'

Others acknowledged boundaries of independent living, but described contradictory practices when asked who they introduce the system to first:

> We have a rule here. If I know the client is forgetful and confused and I see there are emergency contacts listed, I can call them but only if the client is confused, then I would offer to the daughter, but we're not jumping to call them because it's independent living and we respect privacy. If the client names money as a barrier I ask them to let me talk to their son because they might be willing to pay. If the person says no, that means no I cannot go ahead and talk to the daughter. Based on my judgment of the client. This is my way, I don't know what other people do. I don't remember being told. This is my protocol. If I don't trust their judgment and there's a contact person I may call them. I take a very individual approach to everybody.

Another social worker said, "definitely if competent enough to understand, I absolutely talk to [the resident] first." When asked if there are people who do not have dementia but are still considered not "competent enough to understand," she replied, "You know everyone's level of intelligence when you work with them – even some don't understand simple technology. It really depends from case to case. If I see benefit potential and don't think they will understand, I call their children." Bypassing the client to engage family members in the decision making process was a routine practice, though it was not used with every client.

Moralizing discourse. Family members and social workers were not the only authorities pushing for adoption. They also encouraged other residents to serve as spokespeople for the system and a couple of resident users explained that they were "working on" their friends to get them to adopt. This happens one-on-one and in group meetings, as a supervisor described: "We've had times when we encourage other users to come and talk in the small meeting about their experiences and everybody said, but it's the same thing you know your doctor says you should be on your medication, you should take it regularly, but do you take it regularly? It depends on you. So I sometimes joke with them, I say you know that saying, 'you need to lose weight, or the biggest loser is you?'" This statement linking personal responsibility to decision to adopt was representative of another technique social workers employed. Social workers' practice of encouragement drew explicitly on moral discourse surrounding self-care:

> There are residents who you know need it and you recommend and then they still don't want to do it. So that's how I answer questions sometimes when residents say *would you recommend this to your mother*? I say yeah. But it all depends on whether my mother really wants to take care of herself. If she doesn't value herself and she's willing to fall and break her hip then be more invalid than she is then it's her call you know. So sometimes that motivates people to say you know it's true. I say it's all up to you. How much you value yourself, how much you want to take care of yourself?

The moral overtones echo the truth discourse of individualization of risk and personal responsibility for mitigation: "it's all up to you."

Appealing to fear. Social workers employed a third technique: appealing to the fear of being alone in an emergency. Residents feared falling and being unable to call for help. Stories circulated about fellow residents who had died alone in their apartments for this reason. As one technology staff member put it, "I don't like to use fear as, you know, the driver but it seems to work. We did a couple of different flyers and one of the ones that worked really well was you know 'are you afraid of falling and no one knowing?' That was like the header of the flyer. And it explained with a couple of bullet points what the system would do and that kind of drove in referrals…" One social worker was less ambivalent about the use of fear: "The organization tries to sell it by scaring people – *something happened to a lady over the weekend and no one was there!* But when I introduce the system I don't do that. I simply explain what it does and how it differs from PERS (personal emergency response system)." Another social worker explained how she helped a resident envision the system's use after the resident told her "I don't believe in that [passive monitoring]. I will wear my PERS." The social worker responded, "I don't want to scare or overwhelm you, but sometimes you could be unconscious and not able to press the button." This social worker's supervisor also explained how she presents it to residents:

> This is to make you feel independent because if you don't do this then the likelihood of you falling is more, then you would become dependent. So if you depend a little bit of help, I mean you take this help, you're more than likely to stay independent longer. But… if somebody falls this is not going to prevent people from falling, but you don't have to be on the floor for two days you know so that damage control is better. So I am upfront with the clients and I am upfront with the staff. Don't give them that hope that this is there and they're safe.

Social workers walked a fine line of selling a sense of safety and being clear about the system's limitations. They used their knowledge of their clients' chronic conditions and particular

concerns to paint a picture of how the system could be of use in an emergency the resident had already experienced or was thought likely to happen.

  Bargaining. Social workers, together with family members, used passive monitoring as a bargaining tool in the context of inadequate home care options to convince residents to accept the desired outcome – most often to remain living in independent living despite need for support or to avoid having a home aide. One social worker called the technology "a bargaining tool" and explained, "You know…I say 'I talked to your daughter and she agreed you don't have to have 24 hour aide if you use passive monitoring. I emphasize it helps you keep independence, not give it up." Another family member who reported that social workers told her that her mother who was already receiving 24 hour home care needed to be moved to a skilled care residence resorted to more direct threats to force adoption. She explained that her mother said "I don't think I'd like that [passive monitoring]" and that her other family members and friends were "totally against it," citing privacy intrusion. She said, "Then I explained: I'm thinking nursing home or staying in apartment? I won." These negotiations bordered on coercion but when threatened with unappealing alternatives (e.g., use of a 24 hour home aide or move to a nursing home), it was relatively effective.

  Often, two undesirable options with tradeoffs were on the table and passive monitoring was strategically positioned as the best choice for those who did not have Medicaid and could not afford a home aide (social workers explained that those who were on Medicaid declined the system because they tended to prefer "concrete care"). While social workers were adamant that passive monitoring should not be used in place of aide support, they promoted it as a stand-in when aide hours were unaffordable. One explained: "It definitely doesn't decrease aide need or hours. Maybe in the future they will come up with some kind of excuse…I hope not because it definitely doesn't substitute for the personal touch, but I wouldn't put it past the [home care] agencies to try to provide less hours." When asked *Is the system ever used when somebody wants an aide but doesn't have Medicaid and can't afford it?* A social worker explained, "Yes, yeah, that's what we do. Yeah, we do this, because we don't see any other sources, options. To just offer to – at least – at least this system. At least." Social workers were caught in a contradiction due to inadequate care resources; they used passive monitoring as a bargaining tool in care negotiations despite their own experience with it as an improper alternative to aide support.

  Social workers were up against widespread disinterest among residents in using passive monitoring and developed their own persuasive methods. The normative techniques associated with selling the remote monitoring intervention included bypassing residents to engage family members who had more power to influence decisions, moralizing discourse, and the leveraging of fear and technology as a bargaining tool in the context of inadequate home care options.

Reluctant Adoption: The Challenge of Selling

  Those 2% for whom the techniques to encourage adoption proved successful drew on the same risk discourse surrounding independence and risk management of the aging population. Residents who said that they were the ones who made the decision to adopt the technology cited the risk or burden they pose to others, risk calculus such as the probability that they will fall within a given time period, and the idea that adopting is the right thing to do. Some felt vulnerable because they recognized changes in their balance or had fallen. Some decided to adopt because their social worker or family member wanted it. Ineligibility for Medicaid and inability to afford a home aide also influenced their decisions. Others consented to use it but

attributed the decision making power to family or their social worker. The question of who decides whether or not to adopt the technology turned out to be a complicated one. The majority did not accept the system the first time it was introduced and reported that it took social workers between one and six years of continuously bringing it up to convince them to adopt.

Given the active engagement of family members to encourage adoption, it comes as no surprise that a number of residents reported that they adopted it to make their family members' lives easier. This was couched in terms of adoption being "the right thing to do." As a resident in her 80's put it, "I have no either or opinion about it. Like I say I'm only doing it because I think I possibly may need it someday and that would be doing the right thing, I have to consider my daughter too, she's very good." Another woman adopted the remote monitoring system five years after her children purchased the PERS necklace for her when she had returned from a hospital visit. She remembered her angry reaction: "And I came in and I got very upset. I said to my children, I don't want it. I'm not an old lady. I do for myself. What happened to me was my fault you know and I got very angry at them. My son said, mom it's paid for for six months, if you don't want it after six months call up. That day I had written down I called and I got rid of it." This resident eventually adopted the remote monitoring system that came with a PERS necklace after experiencing changes in her health condition. She explained, "My children call me and they say you know mom we can sleep now at night not worrying that you're alone, you're not alone. So they try to brainwash me. I say look I'm not a depressed person I know I need it now…" Like other residents, she experienced conflict with her self-image when it was first introduced by the social worker:

> I was in my mid 80's and I'm still very vain. I still go to the beauty parlor every week. I still put makeup on–I don't go out without makeup. And that more or less put a little…I felt like I was getting old when she first told me about it but I said you know it will satisfy my family, I'm going to get it. It's great and I'm glad that they, they really had to talk me into it but it's a great program for senior citizens.

Social workers reported that conflict with self-image was one of the most common reactions residents had to the system's offer:

> It's not about technology, it's about their attitude about aging. They think I don't want people to think I'm sick. I understand…. Honestly, I don't think [the technology] is great or bad because I've seen both stories and I see how it turns people off. 'It's for older people. I'm not there yet' is the biggest thing…'who said I need help? I'm not there yet. When I'm old.' That's the common response, more than 90%.

Most residents experienced identity conflict when presented with the message that they were at risk and required remote monitoring (for a complete report on reasons for nonuse and discontinuation, see paper 1).

The use of probability statistics to identify risks so they could be managed was evident in the processes of decision making. A current user who made the decision without family pressure remembered who she describes as the director of the housing organization approach her directly to discuss her risk: "He came to talk to people in the building about falling and what you could do about it and I was told that within six months I'm going to fall two times [laughs]. That's over a year ago but it didn't happen. But he was here with a group of people who have been living here and he said he liked me to have it. So that's how it started." For adopters, the sense of being at risk was a strong selling point authorities used to encourage adoption.

Residents were differently positioned to resist the pressure to adopt. A number of residents described the desperation they experienced searching for affordable, safe and clean senior housing before their current apartment opened. Residents often waited 8, and up to 10 years to move into this housing, which was a full step up from their previous apartments. Each expressed gratitude to the housing organization and their residence's social worker. Some residents were grateful for a safe home and trustworthy social worker in the context of a hostile environment outside where they sometimes faced discrimination and communication barriers. Dependency on staff, gratitude in the context of housing scarcity, and coercive family members all obliged residents to agree to adopt.

Discussion

By observing the practices surrounding the selling of passive monitoring technologies in independent living, we see that social workers are acting within a contested space created by the imposition of an intervention on a population that does not, for the most part, want it. Explication of what tend to be coercive methods applied under the banner of doing good by social workers is not original (see Margolin 1997). This study reveals how social workers are caught in a bind trying to negotiate a new sociotechnical practice. Hierarchical dynamics and the specific techniques used to pressure adoption have not previously been linked in the literature on remote monitoring.

The first of two dynamics that come into view is the multiple levels at which power operates. Only a small minority of residents did not reject the technology, and yet the organization's leadership and the technology department declared rejection irrational and left it to their subordinates – the social workers – to push for adoption. The organization and its technology and supervisory staff depended on social workers to do the complicated work of negotiating adoption with residents who were uninterested or resistant without jeopardize existing relationships with clients or family. While social workers had mixed feelings about the intervention, most fully attempted what they were told to do, developing specific techniques in the process.

This pressure to make the passive monitoring program a success trickles down the hierarchy into negotiations with residents, problematizing the nature of independent living. There is a clear conflict between the policy of the organization regarding the right of residents to make independent or private choices and the practices of social workers who justify bypassing residents to involve family. The organization's expressed policy prioritizes the right to self-determination and autonomy. This meant the freedom from being under any form of monitoring, or making the choice not to adopt and having that choice respected. Social workers were also told that the technology supports the organization's mission: to help residents live independently. Caught between two untenable paradigms of independence and risk management, social workers were left having to figure out what independence means: Does passive monitoring enable independence or is independence enabled by decisional autonomy?

The disconnect between the organization's policy and the practices of its staff was made possible by normative logics of intervention that drew on truth discourse about the risk of becoming dependent and personal responsibility for mitigating that risk. Independent choices were often "revisited" and family members were called in to help pressure residents to do the right thing by adopting. In some cases, not adopting was explicitly framed as risking one's

capacity to remain in independent living. Social workers generally framed this as a rational tradeoff: "a little dependence for independence." In this context, deprioritizing residents' right to self-determination was a reasonable thing to do under conflicting orders and pressure from authority figures.

When we look at techniques to pressure adoption and the constrained choices residents are making, we see that they – like the social workers – are not engaged in a fair negotiation. Ultimately, the configuration of many of the problems attributed to the shift to an aging population center on the question of how one should live. *How* is a technical means or practice; *one* is the reflective subject, and *should* refers to values and ethical norms, including those in formation (Collier & Lakoff, 2005). As older adults and caregivers are made into subjects and engaged in self-making through the practice – or contestation of the practice – of remote monitoring, this question is in play. Viewing remote monitoring selling practices reveals how the question of how one should live is prescribed by authorities who draw on dominant gerontological discourses about independence and risk in old age. This research suggests that it is important to begin to understand what is at stake in these negotiations and the potential for conflict between values of independence and risk management.

Conclusion

The majority of the literature about remote monitoring technology use with older adults is concerned with adoption and its barriers but does not address real-world practices involved in encouraging adoption. Evidently, a lot goes into the "selling" of this voluntary service in independent living. The ways in which older adults, family members and social workers negotiate needs, resources, prevention techniques, and risk are relational practices. Despite their ambivalence about the intervention and minimal interest on the part of residents in using passive monitoring, social workers who were tasked with promoting this intervention developed techniques to pressure residents to adopt the system. They bypassed residents to engage family members in the decision making process, used moralizing language, appealed to fears of falling and being alone, and used the technology as a bargaining tool in constrained care negotiations. Older adults' reasons for nonuse must be understood and respected as part of an ethical agenda that prevents passive monitoring from becoming coercive and relieves frontline staff from shouldering an intervention built on untenable paradigms.

<center>**Conclusion**</center>

Remote monitoring technology has been proposed as a way to revolutionize home healthcare by enabling earlier detection and prevention of health events and delaying relocation; however, the processes and social implications of electronic monitoring practices are poorly understood, and these purported benefits have not been fully realized. One of the primary concerns is that its development and research has largely been divorced from the needs and perceptions of users. Researchers have called for work that articulates privacy for this age cohort, as well as how autonomy, independence, and preferred levels of support are balanced in practice. The current project combined original interview data and existing passive monitoring alert records to examine lived experiences with the technology of older adults, family members and staff of independent living residences. The study had four specific research questions: What are the processes involved in decision making about adoption and discontinuation and who participates in what way? What are the procedures of use by social workers and family members? How is privacy in relation to passive monitoring understood and experienced by participants? How do residents, social workers and family members experience passive monitoring and assess its usefulness?

To answer these questions, forty-seven in-depth semi-structured interviews were conducted with 41 residents of independent living, emergency contacts and building staff. The sensor-based passive monitoring system had been offered as a voluntary program to residents for six years at these low-income independent living residences. This is the first study to examine older adults' and family members' reasons for discontinuing use of passive monitoring. It is also the first to examine passive monitoring use by ethnically diverse or first generation citizens.

There is evidence that passive monitoring systems provide peace of mind for some caregivers, social workers and older adults, but that their use requires careful negotiation. Findings reveal that diverse concerns as well as reasons for discontinuing or not adopting passive monitoring use should be respected as part of an ethical agenda and that safeguards at the levels of public and organizational policy are needed that account for a full range of possible psychosocial and ethical implications. Here I provide a summary of the findings followed by specific implications for design, public policy, and organizational policy and practice.

Ethical Issues: Threats to Self-Determination, Autonomy and Informed Consent

Authorities that promote the remote monitoring intervention are multiple and interests are diverse. This mission-driven non-profit senior housing and services organization depended on social workers to do the complicated work of negotiating adoption with an independent living resident population that was resistant. Social workers were under pressure from their supervisors to sell the technology, and the moral positions social workers took were deeply influenced by those who held power over them. This set the stage for four fundamental ethical issues: the bioethical issue of obtaining informed consent and the risk of covert monitoring; threat to self-determination; behavior alteration that threatens autonomy; and the surveillance of nonconsenting individuals.

Informed consent and privacy are significant issues in the use of passive monitoring. These systems produce new knowledge about and enable caregivers to decide how much of that knowledge to disclose. Power to manage boundaries was diminished through passive monitoring

use because residents had to answer for activity that fell outside their normal range and lead to the discovery of private activities and situations. This passive monitoring system was also complex and difficult to explain, leaving some residents unaware of the extent of its features. Without full information about 1) precisely what information is collected and how it is accessed by whom, and 2) knowledge of when it is being used, residents were under the illusion that their privacy was secure behind a set of boundaries they believed they controlled. A significant minority of users could not consent to have a researcher access their alert records because they lacked knowledge about the collection of information about them. Social workers agreed that privacy would be violated if the use of passive monitoring were not voluntary. Without fully informed consent, voluntary use is in question.

Engaging family and peers to encourage adoption, "revisiting" the option multiple times after a resident has declined, and presenting adoption as the right thing to do through moral discourse about self-care are specific techniques that raise concerns about opportunities for resident self-determination. A related concern is that some residents were unaware that family members have online access to information collected by the system. Social workers were reluctant to remind a resident that they have the monitoring system when calling in response to a system-triggered signal. This prevented these residents from being able to appreciate what having the passive monitoring system meant.

The third fundamental issue is the threat to autonomy and control over one's life embedded in the design of the passive monitoring system itself, which does not enable user opportunities for control over the system. The expectation of regularity of routine that is built into the system coupled with no options for the older adult to control it presents a problem for users.

Finally, passive monitoring is used by family caregivers to monitor home care aides, who were not generally informed about the technology. In an interesting power flip, sometimes aides were intentionally misinformed; two residents explained that they had told their aides that the sensors are cameras that are tracking their work. Once some family members recognized that they could use the motion sensors to observe at what times the aides were arriving and at what times they were opening the refrigerators, they decided to take it one step further by installing 360 degree webcams in their parents' apartments. This poses new privacy concerns for aides, visitors and the residents.

Unmet Need and Constrained Choice

The passive monitoring system and its users exist within a larger context in which pressing needs of residents – accessible senior housing in their home community, social interaction, reliable transportation, and affordable home aide assistance – are unmet. A lack of political will to direct resources to solve these problems leaves this independent living organization and its staff with a poorly matched intervention aimed at risk management. This situation, coupled with the lack of standards for who would benefit from passive monitoring contributed to a contested space. Negotiations resulted in constrained choices and would not be considered fair under most circumstances.

These findings recall Aronson's depiction of the narrowness of dominant interpretations of old women's experiences in home care. Drawing on Nancy Fraser's explication of the ''interpreted identities and needs'' used in social welfare that ''are not always recognized as interpretations…and are rendered immune from analysis and critique'' (Fraser, 1989, 153–154

quoted in Aronson, 2000, 53), Aronson (2000) exposes narratives that are preoccupied with fiscal constraints and produce "reductive images" of older adults (p. 52). This allows for desires for privacy and control to be grossly underestimated. These interpretations of needs and the passive monitoring solution designed for them placed residents in the position of having to resist it while negotiating their most pressing needs.

As gerontologists, we know that we tend to construct care as a problem and that we privilege physical and functional well-being over autonomy and emotional and social well-being for older adults. Approximately 98% of the residents declined to use the passive monitoring system and 20% of adopters discontinued. The study of nonuse and diverse forms of use reveal how the priorities of residents to feel safe, in control, and to enjoy privacy and social contact were not comfortably traded with the priorities of the housing organization and family members to enhance safety and risk management in an efficient manner. These are problems of authority and user representation. Ameliorating these power differentials requires reordering whose priorities will be addressed in innovative interventions. Regarding representation, the spectrum of resistance, indicating that the "rational" solution does not deliver desired benefits for these residents, challenges the dominant image of passive subjects of passive monitoring.

Implications for Design

The recommendations offered here take into account the idea that ethical aspects of remote monitoring are not only found in their practices, but are also embedded in the design of the technology. Norms and values about how one should live as an older adult and how one should practice care are embedded in the system through, for example, which end user has control over which functions and whose needs are prioritized. Recognition of how the social is embedded in products is helpful because it allows us to examine the priorities and power dynamics that order them. Placing the priorities of older adults front and center would likely result in solutions that support social connection, control and security. They might target the most obvious areas of need: affordable, accessible housing where people currently live; efficient, dependable transportation; access to consistent home aide assistance; and timely response to emergencies. These are policy issues that are amenable to technological innovation. This research indicates that this is where resources, creative energy and design focus is most needed; however, because the study examined passive monitoring closely, the following recommendations pertain specifically to remote monitoring technologies.

Design systems that create opportunities for boundary management. Through the passive monitoring system, residents were held accountable for their movements and activities in their homes by three parties. Insertion of direct feedback to residents about changes in their activity level before emergency contacts are alerted would enable them to respond accordingly. For example, a resident might dismiss a signal for frequent bathroom use if they understand the cause and are unconcerned. Looping the resident into the system's feedback function could prevent false alerts and incidental findings that threaten their privacy.

Further opportunities for control might include the option to pause the system and restart it when desired. Objections to this design option stem from the realistic scenario that an older adult forgets to restart the system, but can be addressed by enabling an automatic restart. This could include a customizable notification system so the older adult knows it is being restarted or does not if they prefer not to be disturbed. This design principle is particularly relevant when considering the concerns residents had about privacy for intimacy.

A variety of pervasive tracking systems are on the market and in development, such as facial recognition and 3D infrared motion sensing, ingested sensing devices, and wearable GPS devices. The sensitivity and specificity of these devices appear to depend on full omission of opportunities for boundary management, yet boundary management opportunities can be designed in to all of these innovations where there is understanding of the desires and perspectives of older adults. Values are implicitly traded and beliefs and assumptions about particular populations are embedded in the design of these intervention. This research indicates that a design approach that marginalizes older adults will likely result in privacy intrusion and overlooked needs. Implicit values should be made explicit in the design process so they can be tested, challenged, and corrected before they are imposed on users.

Accessibility. A language line is insufficient for non-English speaking users. These residents will struggle with an English-speaking telecare response when they are in an emergency situation. The preferred language of the user could be used in all communication with them. Hearing loss is common in old age; a system that depends on the resident's ability to respond to an audio signal dramatically decreases accessibility. Designers could use device functions known to the Deaf Community such as light and vibration signals.

Diversify user representations and testing practices. More resources might be directed to user research before the product has been developed with a diversity of intended users. Prospective users could be involved through the entire development process to ensure that the desires and needs they prioritize are incorporated into design. Part of user testing should involve product trial in the homes of the engineer and design team members. Putting themselves in the place of older adults would enable designers to learn from personal experience, possibly inspiring new solutions. These findings also show need for products and systems that are streamlined to ease understanding about what they do. System comprehension and appreciation for what will be involved in use could be pre-tested in the lab with older adults before the product is put on the market.

Implications for Public Policy

As of the start of this study, new reimbursement policy for electronic monitoring of LTSS recipients was under consideration at the federal level under Medicaid. A number of states had been pushing for 1915 c/i reimbursement approval for electronic monitoring but categorizing these services under the term "other" within the category "assistive technology," making it impossible for CMS Division of LTSS to know what technology was actually provided. They had concerns that providing agencies may not reveal to the state or CMS what electronic monitoring entailed and what services were replaced by it (i.e. use of video cameras in lieu of on-site staff in congregate housing). Where electronic monitoring of any kind was categorized as assistive technology, CMS was unable to ask followup questions to determine appropriateness of use. New Center for Medicaid Services HCBS regulations went into effect in March 17, 2014 that require states to explain what is being used. These regulations now enable CMS to question these services before approval for reimbursement, allowing them to take into account potential for isolation, community integration, where recipients are living and available services, as well as what protections are in place for data security. States must now explain these technology-based services, their effectiveness, and they must be considered justified for an individual and not applied simply because a facility wants to provide it to all residents.

Going forward, it will be important for CMS to be aware of the ethical issues that can arise when various electronic monitoring devices are used. They intend for clients to have service options. This study indicates that coercion or bypassing fully informed consent is likely to occur among agencies or providers that stand to save money by shifting to use of technology. The current study was conducted in a best case scenario environment with Medicaid and near-Medicaid eligible clients. Even in this environment where financial incentive was low because the organization subsidized the technology, staff pressured residents to use passive monitoring and achieved consent without full comprehension of what data the technology collected and who had access. This is a significant issue for public policy.

An incidental finding with relevance to public policy was the use of cameras by family members without the consent of home aides or residents. Three of the eleven emergency contacts interviewed took passive monitoring to another level by installing cameras with audio in the homes of older adults against the residents' wishes. Other passive monitoring users with 8 hour a day and even 24 hour home aide assistance were adamant that they did not want to be on camera. For all residents, acceptance of sensors was contingent on it not involving a camera. Cameras fall under the category of electronic monitoring and are in use by agencies seeking Medicaid reimbursement. Understanding client preferences with regard to data granularity will be key to ethical integration of these tools into service provision.

Implications for Practice and Organizational Policy

Remote monitoring technologies are marketed and presented as a partial solution to the disparity between need and human and financial resources available to support 'aging in place.' Our knowledge about the use of this technology for helping elders maintain independence is underdeveloped. Social welfare research on this topic is nonexistent, yet the practice of technology use is tremendously relevant to the practice of social work and long-term care policy. Social workers will increasingly come into contact with 'aging in place' technologies in their roles and responsibilities as care managers, resources for family caregiving, discharge planners, and as gerontological social workers.

Clear, consistent policy to prevent coercion. Clearly and widely communicated organizational policy about the selling process and informed consent guidelines are needed to ensure residents' decisions about use are respected. Various scenarios, such as when a family member wants the system but resident does not, might be spelled out with guidelines for each. Protocols or a group consultation process is also needed for clients with various stages of dementia. This might include how to proceed if a resident's condition worsens and she becomes aggravated by the system.

Diversify product options. One size does not fit all. Agreements with multiple companies may prevent over-investment in a particular product and disincentivize attempts to fit the clients to a particular product.

Implement trial period for residents. Informed consent is extremely difficult to achieve in practice and residents adopt without fully comprehending what the system does. In addition to clear policy to confirm that consent is informed, a trial period may benefit residents. Some residents who had discontinued expressed that it was difficult for them to appreciate how having passive monitoring in their home would impact their daily lives and feelings about the space. Allowing for a trial period at the onset may appeal to residents at decision making, and it could

enable a simpler, low-guilt exit process for those who discover they do not want it. Residents who did not adopt reportedly expressed concerns about being "locked in."

      Create a feedback loop with staff. -*Even if I say I don't like something about the system it's not something they can modify. Narratives are insightful but I'm not sure they want to listen to what people think. I feel people don't listen unless they need to, and they don't have much control over it* – Social worker. Staff members encountered similar scenarios, yet developed their own unique approaches for navigating them. Had they been given opportunities to openly discuss challenges and practices in routine meetings, they might have influenced each other and developed better practices. They could work through ethical dilemmas collectively, possibly suggesting practice modifications so that practice experience could directly shape practice guidelines. Work autonomy is an important goal but does not require isolation. Moreover, having the opportunity to be heard and to influence practice guidelines would likely be experienced as empowering. Like residents, it can be difficult for staff to fully appreciate all that selling and using monitoring technologies entails until they gain experience.

      Co-develop personalized procedures. Organizational policy that requires staff to reveal to residents the source of their information at followup may relieve staff from negotiating privacy terms on their own. Resident preferences for how follow-up is conducted could be used to create personalized follow-up questions.

Limitations

      This research was not a close read of resident needs and did not decenter technology to develop a full understanding of what matters most to residents of independent living residences. The study also did not address the impact of continued use on relationships, and these papers are not a comprehensive review of ethical issues involved in practices of remote monitoring.

      Residents who were offered the passive monitoring system and refused it were not interviewed. Data presented here were gathered from interviews with social workers, family members and current users and those who discontinued use. Learning about privacy articulations directly from those who did not want the system, possibly because of privacy concerns, would have strengthened this research. An analysis of how older adults interact with this technology would be strengthened with the perspectives of people who declined adoption.

      The study site was both a strength and a limitation regarding generalizability. The non-for-profit senior housing and services organization was in many ways a best case scenario, with a strong mission-based approach and staff expressing interest in empowering residents and serving as their advocates. This cannot be assumed of other independent living residence providers and may limit generalizability. On the other hand, because this can be considered a best case scenario, findings that reflect ethical problems cannot be dismissed or attributed to the standards of this organization. This study involved independent living residences and the findings may not apply to other residential settings, such as assisted living, nursing homes or private home settings.

      Social workers appeared to feel social pressure to report positive things about the technology, likely in part because the selling and use fell under their purview. Evidence of this included a supervisor's false claim that no residents had discontinued the system for reasons other than a move or death. Still, social workers became more candid over the course of the six-month fieldwork and provided frank responses.

Finally, alert records from the telecare center interactions with residents and emergency contacts were collected for a 12 month period for 10 residents. These data are not reported in detail in these papers, apart from noting that no emergencies were detected through the passive monitoring system while PERS was used in 7 emergency situations. Only ten out of 15 current user residents were capable of consent to have me access their records, which was a finding in itself; however, there were not enough data to run analytics.

Future Research

These findings raise a number of questions. Suggested topics for further study include the relationship between older adults' level of understanding about what the system does and their privacy concerns. Memory loss and passive monitoring raises unique issues and research might address how the development of dementia impacts system use as well as adoption processes. Decision making processes and power relations in other environments like assisted living facilities and private homes is also an important area for study. The use of passive monitoring and web cameras to monitor aides, and by default residents, is an understudied phenomenon with implications for liability, privacy, job quality, relationship building and trust. Best practices for enabling resident boundary management with use of monitoring technology are needed along with systematic tracking of alert records and outcomes to enable the weighing of costs and benefits of use. The current research indicates that understanding the ethical and social issues of passive monitoring requires an examination of actual practices as some of the problems arise in the practices that people develop around the technology. Prospective user studies and short-term pilot studies are inadequate for this purpose.

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