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Active subjects of passive monitoring: responses to a passive monitoring system in low-income independent living

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ABSTRACT

Passive monitoring technology is beginning to be reimbursed by third-party payers in the United States of America. Given the low voluntary uptake of these technologies on the market, it is important to understand the concerns and perspectives of users, former users and non-users. In this paper, the range of ways older adults relate to passive monitoring in low-income independent-living residences is presented. This includes experiences of adoption, non-adoption, discontinuation and creative 'misuse'. The analysis of interviews reveals three key insights. First, assumptions built into the technology about how older adults live present a problem for many users who experience unwanted disruptions and threats to their behavioural autonomy. Second, resident response is varied and challenges the dominant image of residents as passive subjects of a passive monitoring system. Third, the priorities of older adults (e.g. safety, autonomy, privacy, control, contact) are more diverse and multifaceted than those of the housing organisation staff and family members (e.g. safety, efficiency) who drive the passive monitoring intervention. The tension between needs, desires and the daily lives of older adults and the technological solutions offered to them is made visible by their active responses, including resistance to them. This exposes the active and meaningful qualities of older adults' decisions and practices.

KEY WORDS – passive remote monitoring, non-use, resistance, discontinuation, independent living, sensor system, ambient assisted living.

Introduction

A significant innovation in independent-living technologies is the shift from actively triggered social alarms to passive remote monitoring that has even been proposed as a way to revolutionise home health care (Demiris 2010; Skubic *et al.* 2009). Whereas in an active monitoring system, the user has

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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 behaviours (Goldwater and Harris 2011). Data may include vital signs, falls, location, activity, gait speed or environmental temperature. Data recipients are family members, professional and non-professional care-givers, health-care providers, employees of telecare centres and residence building employees. Sensor-based passive remote monitoring systems collect and analyse bio-behavioural markers and deviations from what is considered an individual's 'normal' behaviour, such as a change from their usual number of bathroom visits, which are communicated to an emergency contact for interpretation as signs of a possible problem.

Gerontological research tends to problematise older adults (Estes 1993) and construct them as passive recipients of care; the idea of care is promoted as a problem for care-givers, care systems and policy, an approach rooted in the medical model (Dannefer *et al.* 2008). In the context of discourses on the neo-liberalisation of health care and the demographic shift to an ageing 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 hospitalisations; and provide earlier detection of and improved response to sentinel health events (Demiris 2010; Skubic *et al.* 2009). These interventions are dedicated to the goal of risk prevention.

Researchers have noted that the focus of research on passive monitoring use with older adults has been cost and clinical efficacy (Greenhalgh *et al.* 2013), impact on care burden (*see* Mahoney *et al.* 2008), and acceptance of the technology by older adults and care-givers (*see* Mahoney, Mahoney and Liss 2009). Uptake in the United States of America (USA) has been very slow but appears to be increasing among senior living organisations (LeadingAge and 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 (Courtney *et al.* 2008; EFORTT 2011; Greenhalgh *et al.* 2013; Neven 2014; Peine, Rollwagen and Neven 2014). For example, increasing independence is cited as a primary goal for this technology, but the achievement of this goal is complicated by the fact that stakeholder groups attach different meanings to the word 'independence' (Demiris 2009). Moreover, Mortenson, Sixsmith and Woolrych have expressed concern over unexamined changes in power relations and behaviour alteration:

> The idea of monitoring deviations from 'typical' activity patterns for an individual has interesting parallels with the process of institutionalisation, where the expected patterns become the specific norms against which activity and behaviour is evaluated. The individuals being monitored may begin to change their behaviour if they are concerned about the feedback and implications of their actions, such as triggering alarms, warnings, and contact from caregivers. (2015: 520–521)

The perspectives and actions of actual users are consequently a rich area for inquiry (Courtney *et al.* 2008; Demiris and Hensel 2008; Greenhalgh *et al.* 2013; Joyce and Mamo 2006; Lorenzen-Huber *et al.* 2011; Shankar 2010). Pols (2012) suggests making more room in relation to positive and negative rhetoric for actual users of telecare through qualitative research on that which emerges in practice. Close study of the ways older adults actually interact with and respond to passive monitoring can reveal user representations, values, goals and assumptions to challenge or confirm the product design and care practices on which they are based (Brown and Webster 2004; Lehoux 2008; Neven 2014).

What lessons for researchers, practitioners and designers are contained in the narratives and reported practices of users, creative users, dissatisfied former users and non-adopters of passive monitoring technology in a setting with extremely low adoption rates and high rates of discontinuation? In this paper, the range of ways older, ethnically diverse adults relate to the QuietCare system in low-income independent-living residences are examined. 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 interpretations of independence that cannot be easily rationalised or technologised.

Background: reductive representations and the invisibility of creative and non-use

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) explain that in the eyes of product developers, the user is shaped as a 'good' user who adopts and uses according to design or a 'bad' user who does not. The language employed in research on passive monitoring with older adults reveals the assumptions of this moral gauge, as authors link terms of non-compliance, generational incompetence and paranoia to participants who refuse to use the technology. Non-prescribed forms of use are similarly marginalised; for example, researchers on the multi-country Ethical Frameworks for Telecare Technologies for Older People at Home (EFORTT) study note that when users actively adapt the system to achieve social contact, this is framed as 'misuse' (EFORTT 2011: 21). In what may be considered paternalistic terms, older adults who express disinterest in technologies are considered by designers and providers to have 'initial' resistance as opposed to 'real' resistance (Neven 2014). A problem with this language is that it is dismissive of the actors' intentions; actions are trivialised that indicate practices and ambitions which extend beyond pre-defined, interpreted 'needs' that the technology is intended to address (Peine, Rollwagen and Neven 2014). Instead, the actions and reactions of older adults to technologies might be viewed as a source of inspiration for innovation.

Science and Technology Studies scholars have shown a growing interest in how non-use constitutes something more than meaningless 'negative space' (Satchell and Dourish 2009). Careful not to fetishise non-use, they are beginning to use it as an analytical tool to understand socio-cultural and socio-technical contexts and normative assumptions about what it is to be a user, illustrating how non-use can be 'active, meaningful, motivated, considered, structured, specific, nuanced, directed, and productive' (Satchell and Dourish 2009: 15). They articulate the need to study non-use on its own terms and take non-users 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. (Satchell and Dourish 2009: 15)

In a similar vein, EFORTT researchers argue that respecting the way people 'reshape' technology is an ethical imperative: 'people's creativity in customising systems is actually essential to the "ethical" use of telecare and this customisation process should be respected. In this way telecare systems (in design and implementation) can avoid becoming totalising and coercive' (EFORTT 2011: 16). Diverse forms of use do not necessarily point to failure, but rather, are integral to ethical socio-technical practices.

Greenhalgh *et al.* (2013: 87) describe the literature on technology and ageing as 'framed mostly in the abstracted, rationalist language of gathering, transmitting and processing data', to the exclusion of additional contextualised processes and relationships. Rationalist logics concerned with efficiency do not easily lend themselves to questioning, but diverse forms of use and non-use provide valuable insight into which problems the technology is set up to solve and which it does not. Furthermore, such examination reveals assumptions inherent in the design. Mort, Roberts and Milligan (2011: 154) warn that the foregrounding of technological 'solutions' may 'impoverish both the design and implementation of care services for older people'. They note that care in the form of monitoring may be cost-effective but over-simplifies care, with consequences for elders' psychological and physical wellbeing. What problems are being addressed and what problems are sidelined are appropriate and necessary questions in care technology evaluation (Pols 2012).

Evgeny Morozov 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 optimised if only the right algorithms are in place!' (2013: 5). The critique of technological solutionism is not anti-technology, but rather, anti-reductionist. Quoting design theorist Michael Dobbins, Morozov 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' (2013: 6). Morozov (2013: 13) suggests that designers and engineers would do better to understand the realities in which practices take shape, in all their complexity.

Contemporary gerontology critically examines the definition of old age, and ways of being an older person are said to be expanding (Gilleard and Higgs 2010; Jones and Higgs 2010; Philipson 1998). How elders interact with technologies and built-in expectations for the user should be a treasure trove of expressions of identity and meaning making about topics of interest (*e.g.* independence, safety, privacy and care). Pols' (2012) research has illustrated the contingent nature of care technologies whereby a full range of potential consequences of the technology are worked out between the user and their device. Thus, its impact is not fully predictable.

To analyse these interactions, a conceptual framework based on the principle that values are embedded in technology and technology reinforces values is employed (Lehoux 2006; Oudshoorn and Pinch 2003, 2008; Pols 2012). The 'rational' solutions developed by engineers and designers hinge on assumptions about users that are embedded into technological solutions. These solutions in turn introduce new norms for practices of care and influence user behaviour (Oudshoorn and Pinch 2003; Pols 2012). Technology and age relations are thus intertwined and mutually shaping. That is, the user and the technology are 'co-constructed'.

This idea that technology and users are co-constructed also implies that older adults and care-givers are active and capable of shaping the technology's meaning and use in daily life (Brown and Webster 2004); yet there is conflict between this view and the fact that there is a lack of opportunity for engagement by older adults in passive monitoring. Neven (2014) employs the term 'passive age scripts' to describe this. Passive age scripts result from the inscription of particular ideas about the user population (*e.g.* as frail, incapable, or uninterested in learning how to use or control technology) into a technology designed to minimise opportunities to influence or resist it. How independent-living residents adopt, refuse, discontinue and creatively adapt a passive monitoring system intended to ease care and prolong independence by rejecting this passive age script is the focus of this paper.

The passive monitoring system: how information flows

The QuietCare system consists of five sensors installed in specific predefined locations within apartments. This system is a two-part intervention with a telecare response service provided through a call centre and additional information about activity level accessible 24/7 to social work staff and emergency contacts. Adopters are required to have two emergency contacts willing to respond to alerts generated by the system's telecare centre because social workers are prohibited from acting as first responders in this independent-living setting. Emergency contacts are family members and friends.

The signal alerts are automatically generated through an algorithm and based on a five-sensor system of motion detection. Signals trigger when sensor data indicate that there is (a) a possible bathroom fall; (b) no bedroom exit; (c) the ambient temperature is above or below the set threshold; (d) a significant low level of overall activity; or (e) a significant change in night-time bathroom use. When a signal is triggered, a telecare operator calls the resident, followed by an emergency contact. If no one answers the calls, the telecare operator continues to try to reach the emergency contacts. The exception is if sensors on the door and in the bathroom detect no activity after bathroom entrance, in which case the operator will call Emergency Medical Services (EMS) if they cannot reach the resident or an emergency contact.

The intervention also includes Web-based information intended for prevention. This information is available to social workers and emergency contacts in two formats: a daily e-mail and a log-in website where activity is visually presented by the hour. The e-mail summarises the five features described above along with the relationship between the actual activities of the resident over the past 24 hours and their 'normal range'. Additional information includes 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 night-time bathroom visits. The 'normal range' can be customised (or individualised), 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 social workers and emergency contacts to follow-up with the resident about the abnormal activity.

Methods

In-depth semi-structured interviews were conducted with elder residents, family members, and technology and social work staff of six urban low-income independent-living residence apartment buildings of 150–300 units each in a single metropolitan area of the USA. The buildings are owned and operated by an early adopter senior service organisation that had offered QuietCare to its residents for six years.

Participants and recruitment

The study attempted to include all users and former users of QuietCare, including residents, family emergency contacts and staff. Interviews were conducted by the author with 41 participants: one interview each with emergency contacts, current user residents and residents who had discontinued use, and two interviews with staff members. Residents who were offered the passive monitoring system and refused it were not interviewed because the social workers did not grant access to non-adopters, citing that they were still 'working on them' to convince them to adopt. Social workers stated that interviewing people who had declined the technology would interfere with a potential decision to adopt in the future. Initially, a social work supervisor stated that no one discontinued the technology, which was not the case. It was decided that questioning that misinformation and pushing for access to the former users would be more valuable than achieving access to non-users because reasons for discontinuation are not described in the literature. Achieving access to residents who were dissatisfied enough to discontinue or those who did not want the technology in the first place was a delicate negotiation in the context of strong organisational rhetoric of technological innovation and success.

Each of the ten staff members who had contact with the technology was interviewed. There were a total of 23 current users of QuietCare and 15 were invited and agreed to be interviewed. Of the eight who were excluded, four were unable to participate due to language barriers and four had serious health issues and dementia that social workers determined would impede participation. All eight residents who had discontinued QuietCare within the past year were invited and three declined to participate, for a total of 20 resident participants. Eleven family members were interviewed, and two of them had family members who had discontinued. They were sons, daughters, sisters and granddaughters. Family member participation was lower than that of the residents because some residents declined consent to contact their family members, citing desire for them not to be burdened.

Fifteen resident participants had incomes between US $29,000 and $36,120; five participants had incomes less than $18,050. Resident participants were between 65 and 103 years old with a mean age of 87. All had multiple chronic conditions and most had home aide services. Participants were ethnically diverse with more than half of the residents and staff (22) born in one of ten different countries. This diverse representation is generally reflective of a diverse older population in the USA but the sample is too small to draw conclusions about specific cultural differences. An analysis of cultural issues is the subject of another paper being developed on this topic. All were US citizens.

Staff members of the housing organisation with supportive services were recruited to participate during a routine meeting. The study's purpose was presented and the staff were asked to make contact if interested in learning more about participation. Social workers and their supervisors were interviewed for a total average of 3.5 hours each in two interviews. Social workers contacted their current client users and those who had discontinued over the previous year for permission to give their phone number so that they could be called, the study described and invited to participate. Family members were contacted by the same process with the consent of resident participants.

Data collection and analysis

The interviews were semi-structured. Exploratory questioning, such as 'What does QuietCare do for you?, 'What does it do for [family member]?', 'Tell me about how the decision to use QuietCare was made', was used to understand decision making about adoption and discontinuation, perceived benefit and ways of interacting with the technology. The same questions were addressed in interviews with all participant groups to understand multiple perspectives on the same issues. All but five interviews (out-of-town family members) were conducted in person. Interviews with residents and emergency contacts took place in resident apartments and a quiet restaurant between busy meal hours. Staff interviews were conducted in their private offices with closed doors. All interviews were confidential. Each staff member was interviewed twice in order to understand their processes of use fully.

The analysis was conducted by the author, so extra steps were taken to maintain rigour and accuracy. The multi-step coding processes of grounded theory were employed but a pure grounded theory approach was not. According to methods of grounded theory, methodological and theoretical memos were written throughout the analysis and initial coding of immediate transcriptions of each interview were conducted, allowing this to influence subsequent interviews. For instance, in the first of two interviews, social workers noted extremely low rates of adoption and a high rate of discontinuation. Discontinuation and creative use also represent significant gaps in the literature. For these two reasons, all residents who had discontinued were invited to participate in the study and asked about the specific reasons for discontinuation and the interview guides were adjusted to capture alternative uses. Open-ended questions and probing about specific situations residents had encountered were used in order to capture a full range of uses and interactions with the technology among current users and those who had discontinued (Pols 2012). Staff responses provided in the first interviews were discussed and confirmed with staff in the second interviews. This allowed for the refinement of tentative interpretations and further clarification by participants. Rather than using theoretical sampling, everyone who consented who had any contact with QuietCare at one of the six buildings where it was offered was interviewed, with the exception of eight residents deemed unable to participate due to dementia or language barriers. All interviews were coded beyond the point of conceptual saturation to reduce potential for coder bias.

Transcripts were imported into Dedoose, software that facilitates the management of qualitative data. Open coding was initially used to analyse the interviews in an evolving process (Corbin and Strauss 2008; Glaser and Strauss 1967). In order to organise concepts in a meaningful way, a working codebook with operationalised codes that evolved through the analysis process was developed. Codes were connected to identify patterns and dominant themes through a process of 'axial coding' (Corbin and Strauss 2008). Examples of themes are 'feeling fearful or "spooked" by QuietCare', 'modifying behaviour to avoid alert signals' and 'adopting is "the right thing to do"'. After generating a list of themes, all interviews were read to compare and contrast themes across the interviews and searched for evidence of inconsistencies and contradictions (Corbin and Strauss 2008; Glaser and Strauss 1967).

'Selling' passive monitoring

The housing organisation initially offered QuietCare with the goal of innovating the way independent-living services are provided and with the hope that when the system indicated need for additional assistance, their own home aide agency would be hired to provide additional care. The system did not, in the end, provide financial benefit to the organisation directly, but was heralded as a successful innovation in marketing, news outlets, and collaborations with public and private partners. The housing organisation's social workers were responsible for what they all called 'selling' QuietCare to its residents. While the word 'sell' was used by staff, the organisation heavily subsidised the monthly cost of the system (~$85) and the full installation fee (~$200). Residents paid between $5 and $25 monthly on a sliding scale. In order to promote adoption, particularly among those without Medicaid-covered personal emergency response system (PERS), the organisation subsidised the QuietCare 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.

Staff described two methods used to introduce QuietCare 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. The system was made available to all residents through these group meetings as well as posted fliers throughout the buildings.

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 (98%) 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 per cent, with 2 per cent most often reported. In June 2013, 23 out of 1,075 residents were users (approximately 2%). Six residents, or more than 20 per cent of adopters, discontinued for reasons other than a move or death within a 12-month period. Discontinuation, adoption and non-adoption are discussed below with a particular focus on the less well-explored areas of discontinuation and creative use.

Discontinuation

Those who agreed to use the system but later had it removed reported very similar reasons as those provided by their social workers. The most common reason cited was that the expectation of routine built into the system disrupted their activities and caused them to change their behaviour to accommodate QuietCare, as described below.

Disruptive assumptions about 'normal' habitual behaviour

A number of users who discontinued said they 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 centre. Their concern was often founded; family members reported being 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 responders pounding on their door when residents missed the initial call. A family member of a resident who had discontinued explains:

> It stressed my mom out a lot. QuietCare caused more worry than relieved it because of the late night calls where my only choice was to have the call centre call EMS. My mom started avoiding sleeping in her recliner because she was afraid it would show inactivity and trigger an alert.

A social worker described the events leading up to another 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. One former user explained, 'I felt cumbersome to use it so I got rid of it'. 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.

In addition to the disruption of family members' lives, the disruption to their 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 cognisant 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 12:00 pm: "don't bother me before 12:00 pm", you know? And if the person didn't get up, this is an alert'. Another 85-year-old woman who had a history of diabetic comas along with other chronic conditions was on the whole was very happy having QuietCare, but said she was 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 centre 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 of them had 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, and stayed in the bathroom for longer than an hour. A social worker explained that 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 feeling rushed can contribute to falls; being monitored in this fashion in the space where falls are the most common is likely to be counterproductive as a result. Signals caused by frequent bathroom use were also a problem for residents. As one current user put it, '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'.

It is commonly assumed in the literature and technology discourse 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 behaviour that falls outside a normal range serve as reminders that one will be held to account for deviating behaviour.

Uncomfortable, fearful and 'spooked'

Another theme echoed by residents who had the system removed was experiencing fear, discomfort and anxiety with passive monitoring use. 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 organisation'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 realised 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 apologised repeatedly for not appreciating how the system would affect her before having tried it. Like others who discontinued, she was aware that the housing organising 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 Holocaust 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 social workers explained that some had discontinued because it caused confusion.

Another common reason cited for discontinuation as well as non-use was the fear of EMS being called when a resident was not home, or for a non-emergency. This had occurred more than once in these residences. Social workers and residents explained that 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 non-users who witnessed an EMS visit when their neighbour 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 neighbour 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 visitors would notice the sensors in their apartments, but the EMS visits were significant events that generated shame and blame.

Adoption: active and reluctant

Residents had a variety of reasons for agreeing to adopt and adoption occurred on a continuum between eagerness and reluctance. This continuum was also reflected in their assessment of the technology. Roughly half reported satisfaction and half were neutral or clearly unsatisfied.

Four residents reported that the decision to adopt was made for them by a family member or social worker and were less than enthusiastic about it. 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. 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. A few 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, 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.

Two residents were able to negotiate the ability to stay in their apartments by adopting the system; one's daughter pushed her to adopt it against her wishes in order to justify avoiding the nursing home placement the visiting nurse suggested. The other resident readily adopted and was able to use the sensors to justify disregarding her doctor's order that she not live alone due to sudden-onset diabetic comas ('they [social worker] told me it is like there was somebody else in the apartment with me rather than being alone'). This may have reflected a false sense of safety due to the two-hour lag in inactivity alerts as well as the fact that her living room was a blind spot for the sensors, and yet for this person, independence in the form of living alone in a familiar neighbourhood was integral to her wellbeing and may have been outweighed by this risk. 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 some reported that they benefited from added peace of mind, and most reported that their children benefited from peace of mind.

Creative strategies

Adopters of the passive monitoring system who kept the system sometimes manipulated it to their own ends. Desire for control over fall response and relieving social isolation were primary concerns for the residents.

'Misuse' to exercise control

Falls were common occurrences for some users. 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 emergency room 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 neighbour 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 manoeuvring to outsmart the system and 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.

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

Strategic 'misuse' to combat 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 neighbourhoods 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 neighbourhood ten years earlier because the neighbourhood 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 socialising 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 programme 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 care-givers), the need for social interaction was so pressing that some residents transformed telecare calls into opportunities to chat with the operator. 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 because they empathised with the resident's need for conversation, this was a temporary solution to this resident's problem, and only available to English-speaking users because the telecare centre's use of a language line was an added cost to the centre that 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 centre 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 cause of 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 QuietCare to meet his most pressing needs. Some actively complained while others asked the social workers to discontinue their subscriptions.

Non-adoption

As noted above, approximately 98 per cent of the residents who were offered QuietCare declined it. Non-users were not interviewed and reasons for declining the system were provided second-hand by social workers and other interviewed residents. A supervisor expressed puzzlement about non-use 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'. Social workers reported that the reasons residents provided for not adopting included not wanting people in their business, conflict with self-identity (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. Fewer residents with Medicaid than those without chose to adopt, citing no added value in the sensor-based passive monitoring system over the PERS that Medicaid provides free of charge.

Discussion

This study of non-use, discontinuation and unintended use helps push beyond popular notions of non-compliance and generational incompetency – notions that imply and produce marginality and label the actions of older adults' irrational or deviant (Neven 2014). Challenging this approach by taking seriously all forms of use opens a door to the generative study of the meaningful and active qualities of older adults' decisions and negotiations (Satchell and Dourish 2009). This analysis generates three key insights that contribute to our knowledge of passive monitoring use with older adults: universalising assumptions about older adults have a negative impact on users; 'passive' is a misnomer; and there exists a mismatch between the priorities of older adults in independent living and those reflected in the passive monitoring intervention.

First, values and assumptions that are embedded in the technology (Lehoux 2008) are revealed in this study of the ways older adults interact with it. 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 behaviour or tolerance of disruption. The idea that older adults are creatures of habit and that aspects of one's privacy will be traded for risk management is embedded in the design of QuietCare. These embedded assumptions about older adults are not neutral. When a user does not conform to a routine, the user is asked to justify to three parties those choices and movements that were previously experienced as private. This produced behaviour alteration – a violation of behavioural autonomy. Residents worried that unnecessary alerts would bother family members and expressed a kind of hyper-vigilance to avoid them. Before choosing to discontinue, older adults adjusted their behaviour to accommodate the technology. This need to adjust behaviour to avoid unnecessary alerts reflects a disconnection between the lived experiences of the user and the technology designed for the user. Recall the way a user contrasted the expectations of the technology with her reality, which she generalised to 'old ladies' in an informative tone:

> 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 system played an institutionalising role by policing behaviours such as being in the bathroom 'too long', taking an afternoon nap for 'too long' or sleeping in late. This effect has been predicted (Mortenson, Sixsmith and Woolrych 2015) but not previously explored in empirical research in independent living.

Second, the spectrum of interactions and strategies described here challenge the dominant image of older adults as passive subjects of passive monitoring. The strategies older adults employ would indicate that *passive* monitoring is a misnomer. 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 resisted the expectations of regularity of routine and passivity built into the technological tool. This is remarkable in light of the fact that the technology provided little room for unintended or creative use; it was designed with what Neven (2014) calls a 'passive age script' to be passively received with minimal added burden of learning how to interact with it. Instead, 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'). Ninety-eight per cent resisted it by saying no and holding firm to that decision. This refusal and 'reshaping' are acts that authors of the EFORTT (2011) study argue must be respected and understood as an ethical imperative to avoid 'totalising and coercive' telecare practices. We can learn at least two things from these acts. First, efforts to design care technologies that prioritise total passivity on the part of the older adult are counterproductive. Second, the needs and priorities of older adults are revealed in the ways they reshape the intervention offered them and the reasons they refuse and discontinue it, which brings us to the third insight.

Just as the values embedded in technology are not neutral, neither is the marginalisation of older adults in technology development and service design spaces. In practice, adoption refusal is deemed 'irrational', yet the residents provide reasonable, concrete objections to the ways their lives would be disrupted by the system. Taking non-use, discontinuation and creative use seriously reveals ways in which the priorities of users (*e.g.* safety, control, behavioural autonomy, privacy and human contact) compete with and are more diverse and multi-faceted than those of the housing organisation and family members (*e.g.* safety and efficiency). We see in this mismatch what Peine, Rollwagen and Neven (2014) describe as the predefined, interpreted needs that guide technology development for older adults. The misinterpretations are exposed in the residents' effortful integration and discontinuation of the passive monitoring system. The consequences of these predefined needs are felt by older adults in the form of unwanted disruptions, discomfort, feeling fearful, and autonomy and privacy invasion (for an in-depth discussion of privacy, *see* Berridge 2015). Moreover, the opportunity costs of a mismatched intervention are paid by older adults. This study was not a needs assessment, yet the ways residents (and some social workers) redirected interviews to the problem of social isolation and loneliness makes it appear possible that they would prioritise an intervention into the problem of loneliness over this risk management intervention.

The passive monitoring system and its users exist within a larger context. Certainly, political and economic contexts affect whose priorities prevail and how problems are defined. While the passive monitoring system privileges the need for individual safety, older adults have other needs that reflect gaps in broader US systems – limitations of existing long-term services and supports models, policies which limit available resources for senior housing in neighbourhoods where seniors live, liability issues which mitigate against an employee giving someone a hand to stand up after they have fallen and social exclusion. Social and public health solutions have been relegated to the margins relative to higher-tech health innovation (Lehoux 2008), but these social and public health 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 challenging the dismissive stance that non-use is 'irrational' and that unintended use is 'misuse'.

Limitations of the study

This study involved interviews with building staff, family members, current users and those who discontinued use. For reasons described in the Methods section, non-adopters were not interviewed. The findings presented on non-adoption are the perspectives of staff and participant residents drawn from conversations they had with residents who declined QuietCare. Based on previous findings that residents keep certain information private from their social workers (Berridge 2015), it is likely that residents withheld some reasons for not adopting the system or modulated how they expressed their reservations. The findings about reasons for non-adoption may be incomplete. In order to strengthen these data, each social worker was asked twice in two interviews why residents declined the system and was presented with a list with all reasons previously provided for them to make additions or remove reasons they had not encountered. The reports of the social workers matched each other's. These reasons were triangulated with reports of residents who were current users and those who had discontinued about why their neighbours chose not to adopt. Interviews with those who were offered and firmly declined the technology would strengthen this research. This study involved independent-living residences and the findings may not apply to high-staffed settings such as assisted living or nursing homes. Future research might address each of these limitations.

Conclusion

Older adults are not passive recipients of passive monitoring, and their interactions with the intervention are uniquely informative. 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 and rejection of them. The findings from this research illustrate how responsibility towards users requires attentiveness to the neglected nuances of use and non-use on their own terms. When non-use, creative use and other strategies are examined, we discover how passive monitoring and the reductive understandings of need upon which it is built not only do not deliver desired benefits, but have negative consequences and opportunity costs. Also evident is the need to question the assumption that detecting deviations from an independent-living resident's 'normal' routine is productive. Technology designers and developers might take the perceptions, needs, concerns and desires of older adults as a starting point through methods of participatory design as researchers pursue further lessons from diverse forms of use and discontinuation.

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