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Why older adults and their children disagree about in-home
surveillance technology, sensors, and tracking

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Abstract

Background and Objectives: Despite the surveilling nature of technologies that allow caregivers to remotely monitor location, movements, or activities, the potential differences in comfort with remote monitoring between care givers and care recipients have not been examined in depth. On the dyad and aggregate level, we compare preferences of older adult women and their adult children for three remote monitoring technologies. Their assessments of each technology's impact on privacy, safety, independence, freedom, relationship with family member, social life, and identity are also compared.

Research Design and Methods: This dyadic study employed cognitive-based interview probing and value-centered design methods. Twenty-eight individual, in-depth structured interviews were conducted with 18 women who are Meals on Wheels clients and 10 of their adult children.

Results: Meals on Wheels participants reported multiple chronic conditions and an average of 1.7 ADL and 3.3 IADL difficulties; two-thirds were enrolled in Medicaid. Adult children preferred each technology more than their mothers did and underestimated both their mothers' ability to comprehend the functions of the technologies and the importance of engaging them fully in decision making. Most were confident that they could persuade their mothers to adopt. For both groups, privacy was the most-cited concern, and participants perceived significant overlap between values of privacy, independence, identity, and freedom.

Discussion and Implications: Studying privacy in isolation overlooks privacy's instrumental role in enabling other values. Shared decision-making tools are needed to promote remote monitoring use consistent with older adults' values and to prevent conflict and caregiver overreach.

keywords: *privacy; caregiving; values; technology; dyad; ethics*

Introduction

The surveilling nature of technologies that allow caregivers to remotely monitor the movements and activities of older adults could make such technologies ripe for conflict if not used in accordance with the older adults' preferences and boundaries. The dramatic influx of passive remote monitoring devices has been driven by the promise of benefits of predicting health events, supporting independence, and enhancing safety (Wild et al., 2016; Kaye, 2017); however, the development of devices without the input of older adults (Ienca et al., 2017; Meiland et al., 2017) and without explicit consideration of ethical values (Robillard, Cleland, Hoey, Nugent, 2018) has limited their efficacy and adoption (Ienca et al., 2017; Friedman, Kahn, and Borning, 2002; Berridge, 2017a). The use of these technologies poses ethical dilemmas and can threaten core values important to older adults, such as autonomy and independence, privacy, control, freedom and dignity (Alzheimer Europe, 2010; Ienca et al., 2017; Sánchez et al., 2017; Hofmann, 2013; Meiland et al., 2017; Berridge, 2016). These technologies may empower family members to observe, infer about, and react to older adults' movements or behaviors, but we know little about how caregivers' and care recipients' assessments of these monitoring practices compare.

Research on passive remote monitoring has identified a tension between values of privacy, freedom, autonomy and safety. The way in which older adults negotiate these values is commonly referred to as a "tradeoff" or "sacrifice" (Peek, Aarts, Wouters, 2015). A review of the literature on home monitoring technologies concluded that older adults will trade privacy for autonomy, or the ability to remain living independently (Townsend, Knoefel, and Goubran, 2011). In another study with a high rate of acceptance of in-home monitoring, 60% of users had privacy or information security concerns, and these concerns increased after one year of use (Boise et al., 2013). The "zero-sum" tradeoff framing has been critiqued for its simplistic creation of mutually exclusive perspectives and for its potential to diminish certain values or perspectives in relation to safety (Mulvenna et al, 2017; Cavoukian and Emam,

2010). Moreover, research on passive monitoring's impact on older adults' privacy and independence has not thoroughly drawn out the meanings associated with these values or why they matter to participants (Shankar, 2010).

Researchers have noted potential differences between older adults and family members with regard to perception of need and comfort with various levels of data granularity (Hensel, Demiris, Courtney, 2006; Berridge, 2017b, Lorenzen-Huber et al., 2011) but these differences have not been carefully examined. Family caregivers who become surrogate decision makers are likely to place less weight than older adults on values and preferences related to maintaining autonomy and relationships, and more weight on physical health and safety (Shelton, Orsulic-Jeras, Whitlatch, Szabo, 2018). A study of 266 mild to moderate dementia care dyads found dyadic level discrepancies in beliefs about each of the five care-related values under study: autonomy, burden, control, family and safety. Caregivers consistently underestimated how important each are to the individual (Reamy et al.) The study's authors caution that caregivers will often become surrogate decision makers and at the same time lack an accurate understanding of their loved one's values (Reamy, Kim, Zarit, Whitlatch, 2011).

A small body of research describes negative effects of incongruent perceptions of values held by caregiving dyads for quality of life for both members of the dyad (Moon, Townsend, Whitlatch, Dilworth-Anderson, 2017). Older adult care recipients experience threats to their sense of self (Gomersall et al., 2015), physical and psychological health, and autonomy (Brown, 2007) when their preferences are not accommodated. Given these negative consequences, it is important to compare the ways in which members of care dyads understand and weigh values at play in the increasingly popular care practices of passive remote monitoring. How do dyad members' ideas about impacted values compare, and do family members share an assessment of how important those values are? That is, do members of care dyads agree about the tradeoffs described in the literature? We consider these preferences in combination and in comparison because the negotiation of needs, resources, and risks is

a relational practice. The very capacity to choose an intervention occurs within the context of relationships of dependence (Gomez, Mantovani, and De Hert, 2013).

This study engages participants who are Meals on Wheels clients because they have experience with need for support, in the form of delivered meals, to remain living independently. The participation of a low-income sample of older adults who are unable to leave their home without assistance and who have multiple chronic conditions and ADL/IADL needs is unique. This is an important population to engage because Medicaid is the first third-party payer in the United States to cover passive remote monitoring in Home and Community-Based Services (HCBS) (Berridge, 2018), yet there is very little research on this demographic's needs and preferences regarding technology-based services.

In this article, we present a systematic comparison of mother-adult child dyads' assessments of values at play in three forms of passive remote monitoring: location tracking, in-home activity sensors, and 24-hour Web-cameras. This research identifies potential differences between older adults and family members who are likely to exert strong influence over decisions about adoption or who may become surrogate decision makers. We conclude with recommendations for practice and policy to make sure potential differences are represented and considered in decision making. This line of inquiry is pressing at a time of dramatic influx of technologies with a monitoring component and the important ethical issues this has raised and will continue to raise.

Design and Methods

Human subjects' research approval was obtained from the institutional review board at X University.

Sample and Recruitment

Twenty-eight individuals were interviewed in their homes: 18 Meals on Wheels clients and 10

adult children of 10 of the participating Meals on Wheels clients. Twelve of the 18 Meals on Wheels client participants were enrolled in Medicaid, all had multiple chronic conditions with an average of 1.7 ADL difficulties and 3.3 IADL difficulties. Participants were recruited from a mid-sized U.S. city and surrounding area. Their average age is 77 (61-95); 16 identified as white and two identified as African American.

Meals on Wheels only distributed the recruitment flier to those clients who met all of the following inclusion criteria: identify as women, live alone, are comfortable English speakers, and are cognitively high functioning: (“We want to invited people who will be able and comfortable completing an hour-long interview that requires them to understand descriptions of new technologies and express their opinions about them. For this reason, please do not complete the form with people who appear to have dementia or show signs of cognitive decline”). We thus recruited only those participants who Meals on Wheels indicated were able to participate comfortably in an interview. The Meals on Wheels office we recruited through does not conduct cognitive testing and requested that we do not for consistency with their policies. We did, however, ask participants questions about their ADL and IADL limitations. We limited our sample to women because older adults who live alone and are candidates for passive monitoring technologies are overwhelmingly female.

At the conclusion of each Meals on Wheels client interview, the participant was asked to identify the family member who is their primary support person. Clients who identified someone who lived within a 3-hour radius were asked for permission for the state Meals on Wheels office to call that family member to request permission for the researchers to call them. Because Meals on Wheels clients were our first point of contact, we interviewed an additional eight people who could not identify a support person to be recruited. Those interviews were also analyzed to confirm data saturation for the older adult participant group, but only the 10 who were members of participating dyads are included in the dyadic analysis and are cited here.

All of the referred family members who agreed to participate were adult children. Their average age was 50 (28-66), and all but one African American participant identified as white. Meals on Wheels clients and their family members were given \$50 each.

Data Collection and Analysis

The structured interview guide was developed from multiple rounds of piloted interviews with members of a senior center. We used this pilot opportunity to learn how best to assess comprehension after the interviewer presents a standard description comparable to that to be used in informed consent procedures. After describing a technology, the interviewer asked participants to describe it in their own words to assess understanding and responded to clarifying questions from participants. Participants in the current study had no difficulty describing each technology clearly. The interview guide was greatly improved through that process of refinement during pilot studies.

All participants were interviewed separately by the first author in their homes privately and were audio recorded. Separate interviews allow participants to reveal information to the interviewer without revealing it to others (Eisikovits & Koren, C, 2010). This also allows for analyses of the dyads as a third unit without corrupting the individual interviews (Eisikovits & Koren, C, 2010). Each interview lasted 45–90 minutes.

The interviews focused on location tracking, sensor systems, and cameras. The in-depth interviews were structured around a series of scenario vignettes in which the three categories of technologies were described, one at a time, followed by the same set of questions to elucidate how participants deliberate about the use of each technology. In pilot studies, we learned that creating comfortable distance with an initial vignette about a fictional person (depersonalized vignettes) resulted in more discussion and an easy transition to discussing what the participant thinks of the technology for themselves. The fictional person is “Theresa,” who is referenced in excerpts below. An example of a

description of a technology and depersonalized vignette featuring Theresa, followed by personalized questions, is provided in Appendix A.

Data collection included cognitive-based interviewing probing to understand participants' meanings of central concepts (Jobe, 2003; Willis, 1999) that have not previously been drawn out. This technique is often used to draw out survey respondents' understanding of specific questions with the purpose of improving the survey questions (Jobe and Mingay, 1989; Rickards, Magee, and Artino, 2012). When a value word such as "privacy" or "independence" was spoken, participants were asked to explain what it means to them. For example, "Could you tell me specifically what types of things you were thinking about when you said 'privacy.'"

This study's methods are also innovative in the use of a value-sensitive design technique, an approach to account for human values in the design of information systems (Friedman, Kahn and Borning, 2002). Drawing from this approach, each of seven values was printed in large font on a card, and these cards were presented one at a time in random order: safety, independence, privacy, freedom, relationship with family member, social life, and self-esteem. Each card was followed by the question: How would it [the technology of focus] affect "X value?" Each value has the potential to be described as being positively impacted, negatively impacted, not impacted, or some combination by the technologies of interest, reflecting the technologies' "dual performative potential" (Lehoux, 2006). These value cards were used to ensure that each participant had the opportunity to speak to the same set of values. Before the value cards were presented, participants answered open ended questions about what they thought of the technology.

The adult children of a subset of the client participants were interviewed using the same protocol with adjusted orientation (i.e., "for your mother") and some additional questioning about how they would go about making decisions about the use of these technologies.

All interviews were transcribed verbatim and imported into Atlas.ti. Qualitative methods of dyadic analysis were paired with analyses of individual interviews to create a third unit of analysis, the mother-adult child dyad (Eisikovits & Koren, 2010). Dyadic analysis is a developing methodological approach that embraces the interdependent relationship between individuals as a source of information rather than control for it (Caldwell, 2014).

Analysis occurred in two main steps: “Open” and “axial” coding techniques of grounded theory were used to analyze the interviews individually, followed by analysis of each set of dyads (Eisikovits & Koren, 2010). We first analyzed data from each interview of the dyad as a single unit (Eisikovits & Koren, 2010; Polak & Green, 2016) through an evolving process of open coding in which concepts were delineated and defined through the development of a codebook (Corbin & Strauss, 2008; Glaser & Strauss, 1967). Examples of open codes are *feeling ambiguous*, *anticipating disagreement with dyad member*, *anticipating agreement with dyad member*, and *worries about behavioral autonomy*. Categories of codes were organized to produce explanatory themes (Corbin & Strauss, 2008). For example, *values cannot be easily separated*, and *adult children anticipate power to persuade*. This enabled the next step of within-dyad and aggregated comparisons of the two participant groups.

We proceeded with dyadic analysis by examining the themes and areas of agreement and disagreement from each mother-adult child dyad. This was accomplished through side-by-side readings of individually-coded dyad members’ responses to the same questions, dyad by dyad. Areas of agreement and disagreement were identified through closed coding and documented on an Excel spreadsheet matrix, indicating areas of agreement and disagreement for each dyad by each technology.

All interviews were coded by the first author and a doctoral candidate research assistant beyond the point of conceptual saturation to reduce potential for coder bias and to ensure that all voices and a full range of articulations and their relative emphases within this sample are incorporated into the

analysis. Throughout the data collection and analysis period, the study team kept methodological and theoretical memos as records of the development of analytic ideas and decisions (Glaser and Strauss, 1967). The coding of all interviews by two researchers followed by consensus meetings to make final coding decisions helped to ensure the validity of the findings (Miles and Huberman, 1994; Patton, 2002).

Initially, the dyadic analysis procedure is similar to that performed in qualitative studies on the individual level: highlighting significant statements, sentences, and quotes that provide an understanding of how the participants experienced the phenomenon. This is called horizontalization, developing clusters of meaning from these significant statements (Creswell, 2007; Patton, 2002) by cross analysis, leading to the construction of themes through a back-and-forth cyclical movement between the levels of analysis (Creswell; Moustakas, 1994; Shin, Kim, & Chung, 2009). Unique to dyadic analysis is the examination of the themes emerging from each couple's individual narratives. This is performed by assessing contrasts and over-laps between the individual versions. The dyadic view led to various reconstructions of the existing themes and the emergence of unique sub themes. The complexities involved in such analysis are demonstrated and discussed in the remainder of this article. It should be added that we, as researchers, analyzed the data separately and compared our interpretations on an ongoing basis, to achieve intercoder consensus. In the case of divergence, we discussed the interpretations until we reached a joint version on which we could agree (Patton, 2002).

Results

Adult Children Underestimate Mothers' Comprehension of Technologies

After each of three technologies was described, older adults and family caregivers were each asked to describe their function in their own words. Comprehension was considered achieved when participants stated what information is collected, the recipient, and recipients' mode of accessing the information (eg., *My daughter could see on her phone where I go when I leave the house*). All of the

participants expressed comprehension of all three technology types based on the scripted descriptions. These participants were able to understand and could thus reflect on their preferences for each.

Adult children were asked if their mothers would be able to understand the basic function of the technologies and all (10 of 10) responded that they did not think their mothers would, greatly underestimating their capacity for comprehension. Seven of the ten felt that it would not be important that their mother fully understand. For example, when asked “How important is it that your mother understand what this technology does?” a daughter explained:

I don't think that she would know – need to know all the details, as long as she knows that, you know, I'm going to be placing a camera within the apartment and we just want to be able to check in on her, like monitor on a visual basis. But I don't think she would need to know the details. Yeah. Sometimes the less – the less, the better. Yeah, because then it would seem too imposing.

Consistent with this finding, nine of the ten adult children were confident they could convince their mother to allow them to use monitoring technologies, widely perceiving that they have the ability to persuade their parents to adopt. This was expressed in diverse ways, from discussion of the importance of “how I frame it” to “I could get her to do anything I wanted.” Adult children expected initial resistance and eventual acceptance (e.g., “Mom would resist, but I could get her to come around”). In some cases, adult children predicted conflicting views, stating, for example, “My mother would hate that, and I would love it” and “As a caregiver, I want it, but if I were my mom, I would not.” Even in these cases, adult children thought they could convince their mother to see monitoring their way should the adult children decide a particular technology would be useful to them. This was true for adult children who rated the technologies unfavorably and for those who felt it would be important to be transparent. A son explained in response to the Theresa vignette:

Well, I think if you're trying to convince anybody they have to be clear on exactly what it is. I don't think there can be any room for doubt. You'd have to like lay it out very cut and dry. This is this, this is this, and this information goes here. The purpose for this information is this, you know, you would have to. And I think, I really can't say for sure, I think my mother could probably eventually be uh, persuaded, because my mother, as long as it's coming from an authority figure, I think that eventually she could be swayed to. As far as me [as the future care recipient] and "Theresa," no, that's just you know too far -- too much even for the right purposes.

Adult children expected that their mothers would not comprehend the technologies and expressed confidence that their mothers could be persuaded to adopt a given technology if their children found it useful or if it were recommended by a medical provider.

Divergent Assessments

Adult children assessed each of the three technologies more favorably than did their mothers. When members of dyads approved and disapproved of the same technology, these disagreements consistently involved positive assessment by adult children and negative assessment by mothers.

Mothers, on aggregate, considered the location tracking, sensors and cameras as progressively more invasive and less appealing forms of monitoring. This qualitative work is not intended to produce generalizable quantitative findings; however, in order to provide an understanding of relative preference, we note the number of mothers compared with adult children who stated that they were open to considering use now or in the future: location tracking: 6/10 mothers and 7/10 adult children; sensors: 3/10 mothers and 6/10 adult children; cameras: 1/10 mother and 7/10 adult children. A mother, for instance, responded unfavorably to the hypothetical scenario of "Theresa's" children suggesting she have sensors:

I think her children are really being good, they want to take care of her. And she [Theresa] wants them to mind their own business. I think the whole thing is terrible. She has no privacy. How many times she goes to the bathroom, when she gets up. Oh, and when she has people come in. Hm. I think that's terrible (laughs). She'd feel like it's the Gestapo checking on her.

This mother was opposed to sensors for both "Theresa" and herself, yet her daughter anticipates her acceptance of them: "My mom is very adaptable and cooperative. Yeah. She wouldn't mind any of it. If she knew that it would be helpful to take care of, um, her and also to keep the family at ease, she would cooperate." This case is exemplary of dyad disagreements in which mothers described privacy problems and adult children suggested their mothers would be amenable to use if they felt it would help relieve their children.

The use of Web-cameras is particularly divisive. The Web-camera was the technology that caused the most within-dyad disagreement. More than half of the dyads expressed opposing views, with adult children favoring use. We also observed an unexpected phenomenon. The three adult children who stated that they were already considering use of a camera with their parents claimed that a camera would have no effect on privacy whatsoever. In these particular dyads, their mothers opposed use of Web-cameras in strong terms, citing privacy as the primary violation, while their adult children stated confidently that privacy would not be affected. A daughter, for example, explained:

I don't think she would feel like her privacy was going just by me monitoring her on a camera. I think she'd feel safer. I don't think she would mind if it was just in regular rooms, not near the bathroom. I don't think she would mind. I actually thought of doing that. So I could keep an eye on -- like something happens to her, I can see. I could see if she's okay. I'm still thinking about it.

This participant's mother opposed Web-cameras vehemently in her own interview. This finding of conflict in the use of the most invasive technology of those studied underscores the importance of examining what is felt to be at stake, which we turn to now.

Privacy Matters

For both groups, privacy invasion was the most-cited objection to each of the technologies. Mothers and their adult children had remarkably similar notions of what privacy means. For mothers, privacy meant: To do as I please; To not be told what to do or how; Do something in private - without people knowing things about you; Being alone; and Not feeling watched. Adult children stated very similar meanings: Feeling unrestricted regarding how you lead your life; Not having others know your business; Being in personal space alone; Not being monitored; and It's individual and personal. Interestingly, this shared understanding of the meaning of privacy did not translate into agreement about the importance of the negative impact the technologies could have on privacy. Both groups placed value on privacy and articulated its meanings in similar terms, but they did not always agree on how privacy would be impacted or traded.

Values are bound and intertwined. Participants also perceived overlap and even interdependence in values of privacy, independence, identity, and freedom. For instance, some linked privacy to dignity and self-esteem. This was illustrated by the observation by an adult son that "The more and more one feels one's privacy is being invaded, the more and more degraded some can feel." Participants frequently connected autonomy to privacy. Another adult son explained this connection: "There is some level of privacy that's taken away, and depending on the person, it could affect how they lead their lives or how they feel like they can lead their life. Your life is open and exposed in a way that it wasn't." Mothers spoke in similar terms, suggesting often that opportunities to "cheat" or the freedom to be noncompliant would be at risk when their privacy is invaded. For example, a mother stated:

“I wouldn’t feel good because I’d be afraid to do anything because I know the camera’s watching.”

Interviewer: “When you say afraid to do anything, can you give me an example?”

Participant: “Uh, suppose I’m not supposed to cheat and I go (laughs) in the refrigerator and get something.”

In many situations, observing behaviors is precisely why a family member wants to use the device.

A majority of mothers indicated some concern about the possibility that these technologies could invade the privacy of romantic relationships. This was expressed in terms of wanting the freedom to decide what to tell adult children about personal relationships, including the fact of same-sex relationships. A mother explained this in relation to sensors: “She may love someone and um, they may think, uh, she’s crazy because she loves someone at her age. Uh, it could be another woman and uh, they don’t like that...” This mother did not approve of the sensors and would not want them used with her. At the conclusion of the interview, she told the interviewer that she is in love and described how good being in love makes her feel, likening it to being age 35 again. Romantic relationships and the ability to keep them private were priorities that many of the participants feared would be put at risk by remote monitoring practices.

Room for Ambivalence and Decision Making Support Are Needed

In their verbal processing of the ways in which location tracking and sensors would impact their lives, ambivalence was sometimes expressed, particularly by older adults. Participants spoke about location tracking in positive terms of enabling independence and feeling freedom to go out, confident in their safety should a fall occur or if they should need help when outside in neighborhoods they perceived as dangerous. Mothers wanted children to know where they are in case someone tries to

cause them harm, but the same mothers expressed concerns about their children having this knowledge about their location. One mother's comment illustrates this ambivalence:

"Gosh, you know, that's a – that's a touchy one really. I can see where it could maybe make them more comfortable because they could check on her all the time, but I'm not sure if Theresa would appreciate (laughs) being checked on all the time, you know? Well, there's pros and cons on this.....I guess it would be alright."

Later in the interview, this mother stated: "I – I – I guess I should feel that – appreciated enough to – that they're that interested, you know? And they're that concerned about my life and my safety. Maybe that's the way I should look at it." Similarly, some adult children spoke openly about the complex nature of these decisions. This adult daughter, for example, struggled to respond confidently about her own preferences:

If I were ever presented with these options at discharge from rehab or whatever, I would feel confused about what to do. It doesn't seem clear cut to me. Everyone has the right to fail, and everybody's predicting, (laughs) you're not going to be able to make it, or they've got recurring things that have happened. I feel like that's where it gets confusing to me, like in her kind of a case [participant's mother's], you don't know which way to go, if it's going to cause you more anxiety, if it's going to take privacy or independence -- Not really independence. It gives -- I think it's clear that it kind of doesn't give -- I don't know. I don't know if it gives independence. That bottom line, I just feel like it is a pretty confusing area for certain kinds of individual situations."

The ambivalence these participants expressed indicate that for some, the right decision will not be cut and dried and may require decision making support and the opportunity to test run technologies or revisit decisions.

Discussion and Implications

This study describes two clear trends in which adult children prefer the passive remote monitoring technologies more than their mothers do, and adult children underestimate their mothers' ability to comprehend such devices. We found no instance where a mother favors a technology and her adult child does not; in every case of incongruence, the mother viewed the technology unfavorably and adult child viewed it favorably. This finding aligns with research on how family caregivers who become surrogate decision makers are likely to place less weight than do older adults on values and preferences related to maintaining autonomy and relationships and more weight on physical health and safety (Shelton, Orsulic-Jeras, Whitlatch, and Szabo, 2018). The finding that cameras prompted the most incongruent views is concerning in light of their more invasive nature from the perspective of older adults and the anticipated harms to values of privacy, independence, freedom and self-esteem.

Contrary to adult children's expectations, we found that it is possible to achieve understanding of the basic functions of a location tracker, activity sensors, and monitoring camera among low-income independently living older adults with multiple chronic conditions and ADL/IADL needs who have difficulty leaving their home. These findings reveal that achieving informed consent or knowledgeable participation by older adults in decisions about monitoring technology is probably less difficult than presumed. Unfortunately, this underestimation has negative implications for the extent to which adult children would seek informed consent from their parents or involve them in decision making.

Participants spoke about values at play in remote monitoring practices that aren't easy tradeoffs. They perceived overlap and interdependence among values of privacy, independence, identity, and freedom, highlighting privacy's instrumental role in enabling and protecting these values. This finding that values are interconnected challenges researchers' common framing of preferences in terms of an acceptable "tradeoff" that posits that they are exchangeable instead of intrinsically linked.

This framing assumes that older adults would 1) trade values in the same way and 2) that values such as privacy and autonomy do not actually depend on each other, such as when an invasion of privacy impedes one's sense of independence when they are reprimanded for "cheating" with food. According to this study's participants, privacy is not just an intrinsic value that is valuable for privacy's sake, but rather, it is integral and necessary to enjoy other values like freedom, independence, and identity. Much of the aging and technology research has been driven by an interventionist logic, focused on validating a technology's acceptability (Peine & Neven, 2019), yet our findings align with critiques of the tradeoff framing that is often used in this work because it has the effect of oversimplifying older adults' experiences (Mulvenna et al., 2017; Cavoukian and Emam, 2010). Our participating dyads did not always agree on how values would be impacted, or if these values could be traded.

Most adult children expected some resistance from their mothers, but they overwhelmingly reported confidence in their ability to persuade adoption. This finding aligns with a phenomenon identified by Neven (2010; 2015) who discusses the paternalistic idea of "initial" vs. "real resistance" to describe older adults' resistance to technology use. Peine and Neven (2019) note that older adults too often are dismissed as technological laggards and Berridge (2017a) has shown how independent living residents' preferences can be overridden or dismissed as "irrational." Under these assumptions, Peine and Neven write, "acceptability problems...are easily framed as the consequence of technology-skepticism" (2019, p.17). Our findings indicate that caregivers and care recipients may have different understandings of what is at stake in monitoring practices, and these are rooted in values that they take seriously and may weigh differently.

Policy and Practice

This inquiry is timely because these three specific technologies are now reimbursable in some states through Medicaid HCBS waiver programs, and Managed Care Organizations are exploring how

they can be integrated into managed LTSS (Berridge, 2018). Medicaid program managers predict family conflict in these decisions and report struggling to determine in what circumstances would siding with the caregiver be ethical (Berridge, 2018). Due to this growing use that will demand the development of best practices and policies to ensure appropriate and effective use, it is imperative that research address this critical knowledge gap. This is particularly urgent if we are to keep in focus the empowerment of older adults when caregivers wish to access new information about them.

This study's findings indicate that we can expect overlapping and diverse and competing priorities from older adults and adult children. The dissemination of technologies that passively collect and transmit personal data is outpacing our understanding of how to help families think about and involve older adults in decisions about how they want to be monitored. When families are not equipped to make informed decisions about technology use, they are unlikely to benefit from it. Pragmatically, it is wasteful when families invest in technologies that don't work for them. The potential is lost for passive remote monitoring to enhance autonomy and empower care dyads.

Maximizing the potential benefits requires the right balance and respect for boundaries that are specific to each family. Ethical use requires older adults be involved in decision making to the extent possible (Alzheimer's Europe, 2010). Involvement in decisions about monitoring recognizes their personhood and the fact that they have preferences that can be expressed (Whitlatch, Feinberg, and Tucke, 2005; Whitlatch, Piiparinen, and Feinberg, 2009), yet adult children may not be inclined to seek their involvement for reasons described by our participants of wanting to avoid conflict and the misperception that their parent won't comprehend the technology. Whenever possible, older adults should be fully informed about the monitoring technology and its possible implications.

The shift to passive remote monitoring presents new threats to values that matter to older adults. Because the care dyad (or care triad, etc.) is where the negotiation of these values occur, this

research is a critical step towards developing practices to ensure that we uphold the values that older adults care about as remote monitoring technologies are implemented. The findings presented here indicate that families require support to identify person-centered values in relation to these technologies and practical tools to select the options that align with those values as needs change. This research about incongruent weighting of values underscores the need to understand and promote ethical application that is attentive to the values that matter to older adults and does not diminish them in efforts to ease caregiving, predict, or mitigate risk. It is our hope that this work helps to articulate and address the challenges these technologies present in order to harness their benefits in ways that do not diminish older adults or their opportunities for quality, life enriching care.

Limitations and Future Research

Interviews were conducted with non-users of passive remote monitoring in order to understand their responses to a range of technologies and to capture views of people who would be considered target users (i.e., homebound with multiple chronic conditions and ADL/IADL needs). Actual use was not studied. Twenty-five of 28 participants were white. The study population is not racially or geographically diverse. The study examined only three technologies. Applied research is needed that is responsive to opportunities and challenges that come with additional passive technologies now and in the near future: for example, the rapidly-developing need to understand how to effectively incorporate artificial intelligence and digital medications that introduce challenges to values like privacy, autonomy, and mutuality.

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Appendix A: Example Vignette and questioning for GPS location device*

I'm going to tell you a couple of stories and ask you to imagine how the people in the stories might react to these technologies. After I explain each one, I'm going to ask you to tell me about it in your own words so I can make sure I explained it clearly.

The first story is about a woman I made up, let's call her Theresa. Imagine this woman Theresa is 80 and she has enjoyed living by herself in her apartment. Theresa has the LifeAlert button. Theresa recently had a fall and her kids think she is a little forgetful and so are worried about her when she leaves the house. So they ask their mother to wear a device called a location tracker that tells her family her exact location if she leaves the house. Theresa could wear this thing on a watch or on the LifeAlert necklace. Her kids would be able to know when she left her apartment and exactly where she went.

To make sure I explained it clearly, please tell me what you think this location tracker does.

Let's say Theresa's children have asked her if she will use this location tracker. What do you think is in Theresa's mind if she heard that?

[Probing only after initial response]

Value card probing (small laminated cards with each word, presented in random order)

- Safety/Security
- Companionship/Human Contact
- Freedom/ Self Control
- Privacy
- Independence
- Relationship with Children

[Put one value card in front of participant at a time and ask, how you think (X technology just discussed) would affect Theresa's Safety or Security....? How? If no: Why do you say that?]

Is there anything missing from this pile of things that might matter?

Now that we've been talking about Theresa, can you tell me how you would feel about having this for yourself?

*In a pilot study, multiple terms were tested for comprehension. "GPS" was not used in the final guide because participants associated it with googlemaps, mapquest, and other navigation map services, which led to confusion about the purpose of this device.