



Cyber-Security Blanket or Simply Another Stressor

Remote Activity Monitoring for People with Dementia and Their Family Caregivers

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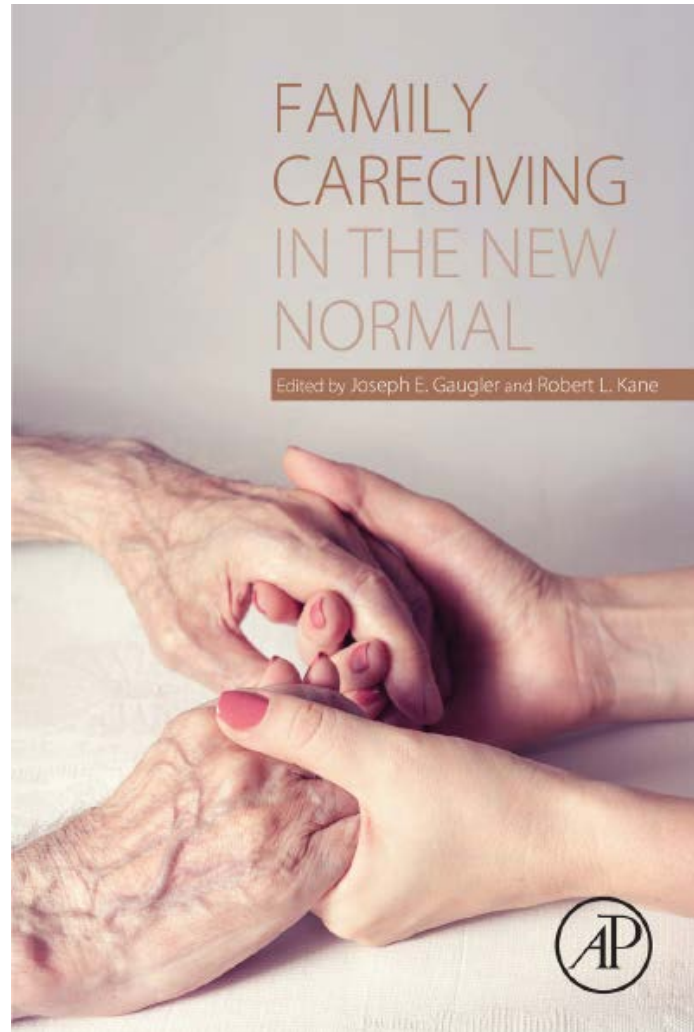
Objectives

- Understand the potential role of remote activity monitoring (RAM)
- Recognize advantages of mixed methods approaches to studying RAM
- Identify barriers and challenges of RAM use
- Describe the preliminary effectiveness of RAM

Public Health Context

- 5.7 million persons with Alzheimer's disease or a related dementia (ADRD) in the U.S. (Alzheimer's Association, 2018)
- Over 16 million family caregivers for these individuals in 2017 (Alzheimer's Association, 2018)
- The majority of care hours (78%) provided to persons with ADRD is from family/unpaid sources (Friedman et al., 2015; Stone, 2015)
 - ADRD family care was valued at \$232 billion (Alzheimer's Association, 2018)

Family Caregiving Burden



Smart Homes and Caregiving

| Functionality | Focus |
|--|--|
| Physiological monitoring | Physiological measurements, vital signs |
| Functional monitoring | Functional measurements including general activity, motion, gate, and meal intake |
| Safety monitoring and assistance | Measurements of environmental hazards (fire, gas leak), assistance turning on lights, and location tracking including GPS-based systems |
| Security monitoring and assistance | Detection of human threats and response to threats |
| Social interaction monitoring and assistance | Measurement of frequency of social interactions including phone calls, visitors, and activities; technology that facilitates interaction including video-based systems |
| Cognitive and sensory assistance | Automated or self-initiated reminders and other cognitive aids including medication reminders, key locators, verbal instructions for using appliances, or sensory deficit aids for sight, hearing or touch |

Adapted from Demiris et al., 2015, p. 215

Remote Activity Monitoring

- Remote activity monitoring (RAM) includes systems comprised of video, audio, and/or motion sensors capable of detecting activity in certain areas of a home
 - Information is transmitted to software and hardware and is analyzed for various purposes, such as issuing an alerts when an activity crosses a threshold that is unexpected.
- It is believed that RAM can allow healthcare providers or family caregivers to detect abnormal activity patterns and allow for responses that are more proactive and efficient.

Prior Research

- Many older adults are interested in the potential of monitoring technologies (e.g., Chaudhuri et al., 2017).
- RAM may contribute to more accurate information on activities and other key caregiving domains (e.g., Wild, Mattek, Austin, & Kaye, 2016).
- There are several barriers to implementing and utilizing RAM, including:
 - Cumbersome devices (Matthews et al., 2015);
 - A lack of user-friendly interfaces (e.g., Preusse, Mitzner, Fausset, & Rogers, 2017);
 - Frequent false alarms (e.g., Nauha et al., 2016); and
 - Unanticipated technological difficulties (e.g., Williams et al., 2013).
- The trade-off between privacy and usefulness of monitoring is an important ethical issue (e.g., Mulvenna et al., 2017).

Prior Research

- There are few randomized controlled studies of the effectiveness of RAM for adults with ADRD or their family caregivers
- Available RCTs feature smaller samples ($N \leq 60$), but suggest potentially positive effects of RAM for family caregivers and older adults (Rowe et al., 2009; Torkamani et al., 2014).
- A recent, larger controlled evaluation implied positive (albeit not statistically significant) trends on RAM users' healthcare costs (Finch, Griffin, & Pacala, 2017).

Current Gaps in the Literature

- Small sample sizes
- Short periods of observation
- Limited research on understand acceptability and utility of RAM
 - Over time
 - Within ADRD caregiving context
- Lack of controlled outcome evaluations

eNeighbor

- Consists of six unobtrusive motion sensors placed in key locations throughout the home of the person with ADRD to detect and verify daily activity.
- The sensors operate jointly and exchange information on movement or function and can detect unusual daily activity patterns.

Passive Health Monitoring

1. Sensors detect a change in behavior
2. Algorithms generate an actionable alert
3. Caregiver provides an intervention



Safety Monitoring

| Monitor | Description |
|-----------------------------|--|
| Passive Check-In | This monitor lets caregivers know a person is up and active for a day. Configurable for call or email by person or population. |
| Out of Bed | This monitor alerts a caregiver if a bed sensor is deactivated- call is sent immediately. |
| In Bed Too Long | This monitor alerts a caregiver if a person is in bed too long- configurable based on time of day, duration in bed. |
| Front Door Open | This monitor alerts a caregiver if a front door has been opened. Call is sent; configurable on time of day and other features. |
| Nighttime Bathroom Activity | This monitor alerts a caregiver if a person may need assistance at night in the bathroom. Configurable on time of day, and length of time away from bed. |
| No Activity | This monitor alerts a caregiver if there is no activity in a home. Configurable based on time of inactivity. |

Dashboard

Healthsense Dashboard

Select Date
Viewing: **07/28/2015**

Previous Resident | Next Resident

Name: Resident 350 | Age: 77

Care Program: [Care program]

Program start date: Dec. 15, 2014

Show activity timeline

Summary of Health Changes (Top 5)

Member had a significant increase in the following:

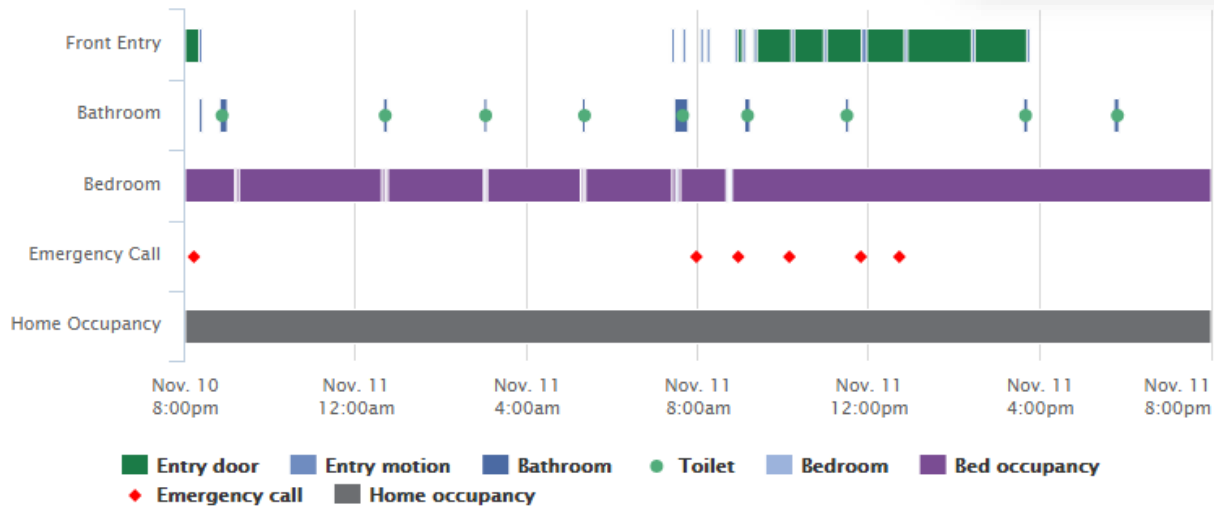
- Kitchen Activity over 15 days
- Toileting over 30 days

Prior to this HealthNote, the most recent HN was sent on July 20, 2015.

Toileting

Healthsense Sensor Data

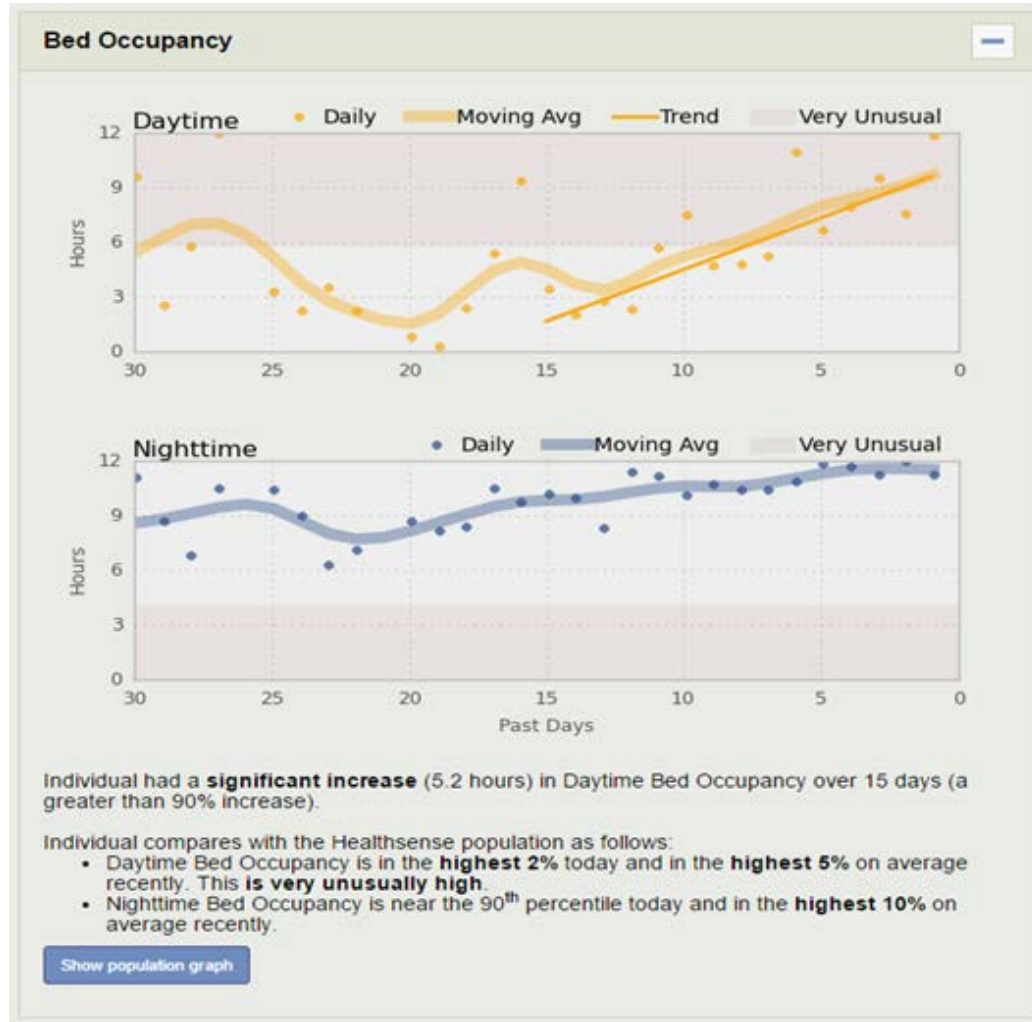
Detailed Healthsense sensor firings for 11/11/2015



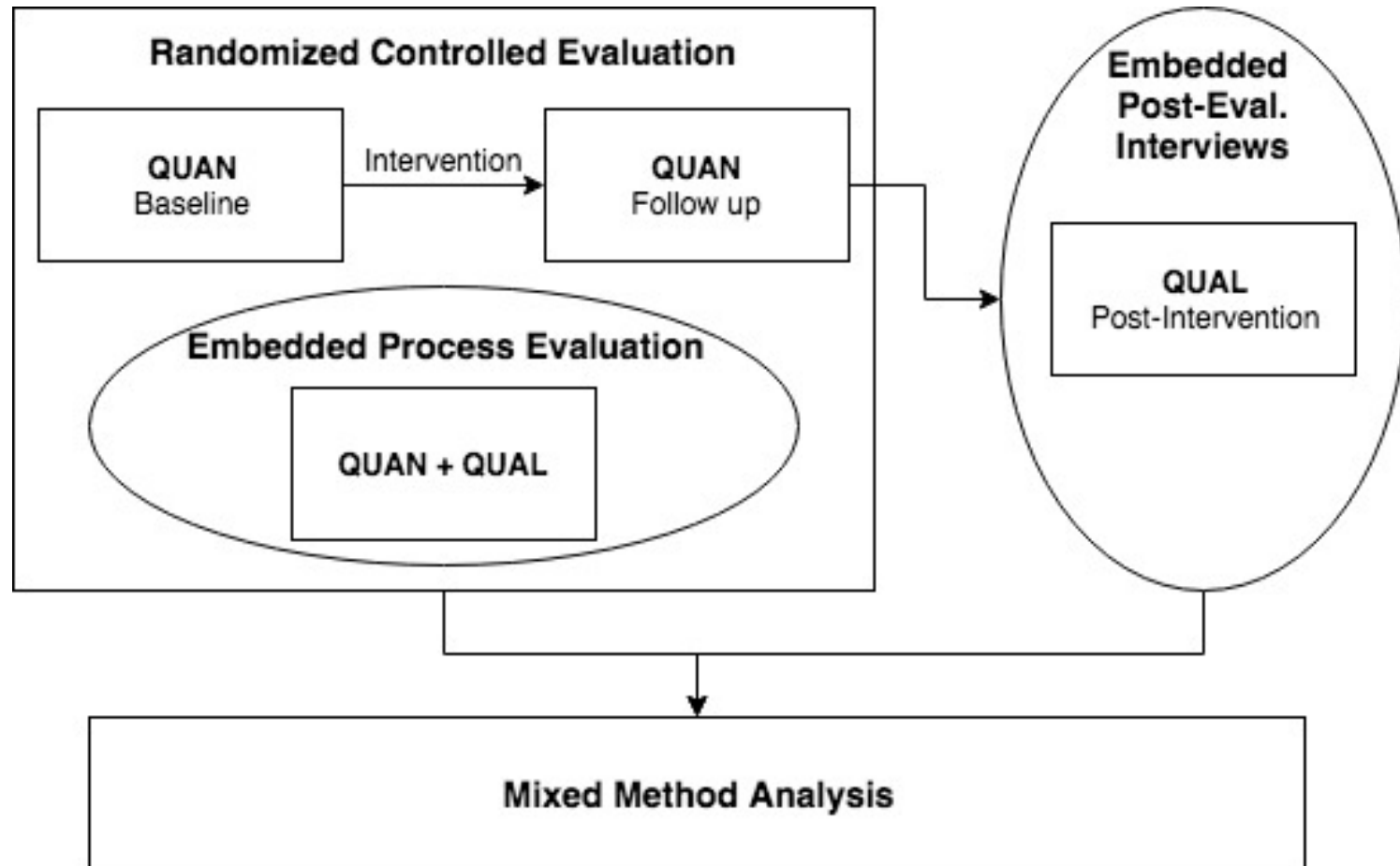
Highcharts.com

Close

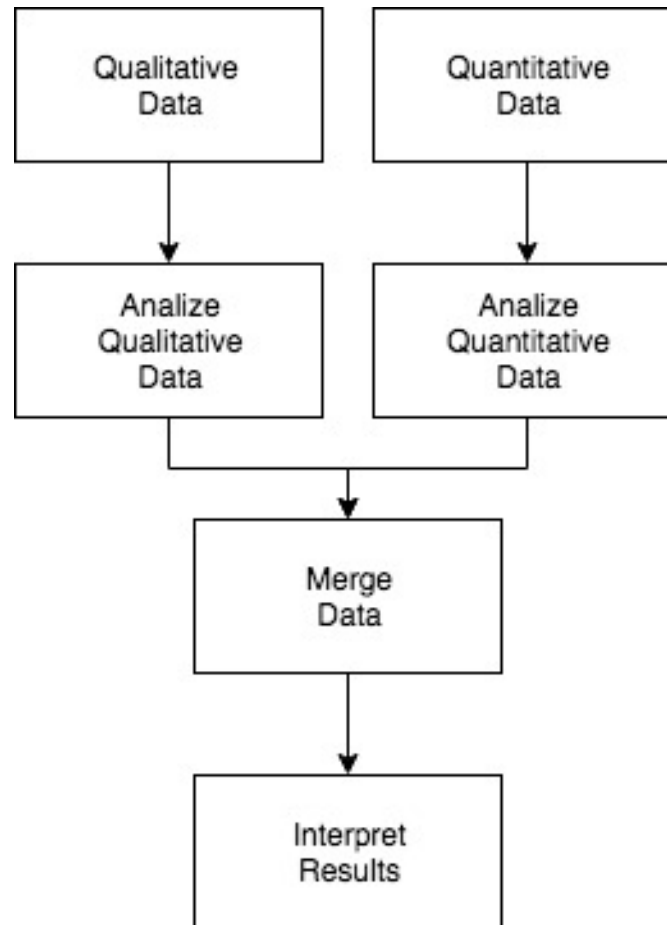
Dashboard



Study Design



Mixed Methods Approach



[Insert Program/Unit Title or Delete]

Study Enrollment

- Participants were recruited via the University of Minnesota Caregiver Registry or through advertisements, community outreach, and presentations
- Care recipient:
 - English speaking
 - Physician diagnosis of ADRD
 - Not currently receiving RAM
 - 55 years of age and over
- Caregivers:
 - English speaking
 - 21 years of age and over
 - Self-identify as primary caregiver
 - Plan to remain in the area for at least 18 months

Quantitative Data Collection

- Context of care
- Primary objective stressors
 - Person with ADRD's ADLs (Katz et al., 1963) and IADLs (Lawton & Brody, 1969),
 - Cognitive impairment (Pearlin et al., 1990)
 - Revised Memory and Behavior Problems Checklist (Teri et al., 1992)
- Caregiver distress
 - Zarit Burden Interview (Zarit, Todd, & Zarit, 1986)
 - Role captivity and role overload (Pearlin et al., 1990)
 - RMBC Reaction
 - CES-D (Radloff et al., 1977)
- Caregiver self-efficacy (Fortinsky et al., 2002)
- Short Sense of Competence Questionnaire (SSCQ) (Vernooij-Dassen et al., 1996)
- eNeighbor review checklist

Qualitative Data Collection

- At the conclusion of the close-ended checklist, caregivers were asked 8-item open-ended questions.
 - “How was eNeighbor easy or difficult] to use?”
 - “Do you feel the alerts generated by eNeighbor worked well? Why or why not?”
- Semi-structured interviews
 - Purposively selected caregivers based on their review checklist responses
 - Took place following completion of 18-month surveys

Preliminary Analyses

- Do family caregivers of persons with dementia perceive a remote activity monitoring (RAM) system as feasible and useful over 6 months and up to 1.5 years?
 - Mitchell, L. L., Peterson, C. M., Rud, S., Jutkowitz, E., Sarkinen, A., Trost, S, Porta, C. M., Finlay, J. M., & Gaugler, J. E. (2018). "It's like a cyber-security blanket:" The utility of remote activity monitoring in family dementia care. *Journal of Applied Gerontology*. doi: 10.1177/0733464818760238.
- Does RAM technology improves key family caregiver outcomes over a 6-month period
 - Caregiver self-efficacy and competence
 - Caregiver distress

Feasibility: Data Analysis

- Descriptive statistics (frequencies, means)
- Correlations
- Thematic analysis of all interviews (n= 7) and open-ended surveys (n=56) by Lauren Mitchell and Colleen Peterson
- Descriptive empirical results of the eNeighbor review checklist were compared to the organized qualitative themes
- A case-oriented merged analysis was also conducted

Feasibility: Baseline Demographics

| Demographic | Caregiver | Care Recipient |
|--|---------------|----------------|
| Female, <i>n</i> (%) | 25 (83.3%) | 17 (56.7%) |
| Age, years, M ± SD | 60.79 ± 11.97 | 77.47 ± 9.09 |
| Caucasian, <i>n</i> (%) | 29 (96.7%) | 28 (93.3%) |
| Married, <i>n</i> (%) | 24 (80.0%) | 16 (53.3%) |
| Living children, M ± SD | 1.86 ± 1.27 | 3.27 ± 2.54 |
| BA or higher, <i>n</i> (%) | 20 (66.7%) | 15 (50.0%) |
| Employed, <i>n</i> (%) | 12 (40.0%) | |
| Income ≥ \$80,000, <i>n</i> (%) | 10 (33.3%) | |
| Providing care, months, M ± SD | 42.70 ± 25.21 | |
| Spouse of care recipient, <i>n</i> (%) | 15 (50.0%) | |
| Income ≥ \$30,000, <i>n</i> (%) | | 18 (60.0%) |
| Lives with caregiver, <i>n</i> (%) | | 19 (63.3%) |
| Medicaid, <i>n</i> (%) | | 6 (20.0%) |

Feasibility: Baseline Objective Stressors

| Measure | Score (M ± SD) |
|---|----------------|
| Activities of Daily Living (ADL) | 2.57 ± 2.97 |
| Instrumental Activities of Daily Living (IADL) | 11.23 ± 4.06 |
| St. Louis U Mental Status score | 11.23 ± 7.80 |
| Cognitive impairment | 2.54 ± 0.72 |
| Revised Memory and Behavioral Problem Checklist (RMBPC) - Frequency | 1.53 ± 0.57 |
| Caregiver self-efficacy | 28.37 ± 6.36 |
| Caregiver Short Sense of Competence Questionnaire (SSCQ) | 23.93 ± 5.60 |
| Revised Memory and Behavioral Problem Checklist (RMBPC) - Reaction | 1.05 ± 0.60 |
| Zarit Burden inventory | 37.70 ± 13.34 |
| Role captivity | 9.23 ± 2.78 |
| Center for Epidemiological Studies - Depression (CESD) | 30.43 ± 9.07 |

[Insert Program/Unit Title or Delete]

Feasibility: 6-Month Review Checklist

| 6-Month Review Checklist | Mean (SD) |
|--|-------------|
| The needs assessment session provided by the Director of Nursing Technology was helpful | 4.41 (0.80) |
| The Director of Nursing Technology has been helpful to me in using eNeighbor | 4.08 (1.16) |
| The myHealthsense portal is simple and helpful | 3.54 (0.93) |
| I felt lost using eNeighbor | 2.44 (1.23) |
| The alerts provided by eNeighbor have been helpful | 3.67 (1.27) |
| The alerts generated by the eNeighbor have helped prevent crises for the person with memory loss | 3.13 (1.33) |
| I would recommend eNeighbor to others in a similar situation as the person with memory loss is | 4.00 (1.11) |

Likert Scale: 1 = Strongly disagree; 3 = Neutral; 5 = Strongly agree

Feasibility: Correlations

- None achieved statistical significance at the $p < .05$ level.

Feasibility: Case Oriented Mixed Analysis

| Dimension Case | 6-Month Checklist | 12-Month Checklist | 18-Month Checklist | Exemplar Quote |
|--|--|--|--|--|
| <p>ID 24</p> <p>58 year-old woman caring for an 85 year-old mother-in-law</p> <p>High Enthusiasm</p> | <p>4.62</p> <p>“In general, I feel better about the coverage we are providing to our loved one. I feel we are doing a better job of monitoring her situation without being too intrusive.”</p> | <p>4.67</p> <p>“I logon several times a day, mostly in the evening and at night, to check on my love one when she is alone in her home and should be in bed. It is easy to see where she is located in her home and watch when she is having a restless night to make sure she does not wander.”</p> | <p>5</p> <p>“It has also built our confidence to leave our loved one in her home and living independently longer than we might have had we not had the system in place so that we know she is safe.”</p> | <p>“It’s just been very, very helpful. And, it’s made us confident in that we can set alarms so we get called at night in specific situations. So again, we feel like we’re being proactive. We’re aware. We’re going to be notified.”</p> |

Feasibility: Case Oriented Mixed Analysis

| Dimension Case | 6-Month Checklist | 12-Month Checklist | 18-Month Checklist | Exemplar Quote |
|--|---|---|---|--|
| <p>ID 38</p> <p>81 year-old woman caring for her 82 year-old husband</p> <p>Low-to-Moderate Enthusiasm</p> | <p>2.86</p> <p>"I set off the alarms myself forgetting they were there and became very frustrated."</p> | <p>3</p> <p>"I probably did not need the monitoring, since wandering did not become an issue so far."</p> | <p>2.86</p> <p>"Do you feel the alerts generated by eNeighbor worked well? Why or why not?"</p> <p>"Did not use them much. Do not think I could answer this."</p> | <p>"Did not think the person with memory loss needed much monitoring, since I am in house. Not like if person living alone."</p> |

Feasibility: Case Oriented Mixed Analysis

| Dimension Case | 6-Month Checklist | 12-Month Checklist | 18-Month Checklist | Exemplar Quote |
|---|--|--|---|---|
| <p>ID 11</p> <p>54 year-old man caring for his 90 year-old mother</p> <p>Adaptation/Acclimation</p> | <p>3.24</p> <p>"I lost lots of sleep when the phone calls early in the morning, after that I just could not get going in the morning."</p> | <p>4.48</p> <p>"I didn't like the phone calls so late at nite-early morning but it also told me something was going on, an early detection of an infection, so then I will get a urine sample to get tested and every one was right on..."</p> | <p>4.29</p> <p>"98% of the alarms told me when my mother was having UTIs and I would work that into getting her to a urologist, just to prove she was having an infection, that was because she was not in bed but wandering around the house..."</p> | <p>"[eNeighbor] always confirmed my thoughts on when the UTI was coming. Cause that way I could always go by that. And then I can always say, well, she's getting a UTI, you know. And pretty much all the time I was right."</p> |

Feasibility: Mixed Method Results

- Fit of RAM: Context Matters
 - Did not fit my caregiving situation
 - May fit others' caregiving situations

Feasibility: Mixed Method Results

- It Takes Time
 - Technical issues (false alarms)
 - Staff support

Feasibility: Mixed Method Results

- Benefits to caregivers and care recipients
 - Provided useful information
 - Promoted peace of mind
 - Was easy to use
 - Prevented health crises
 - Promoted independent living
 - Desire to keep the system

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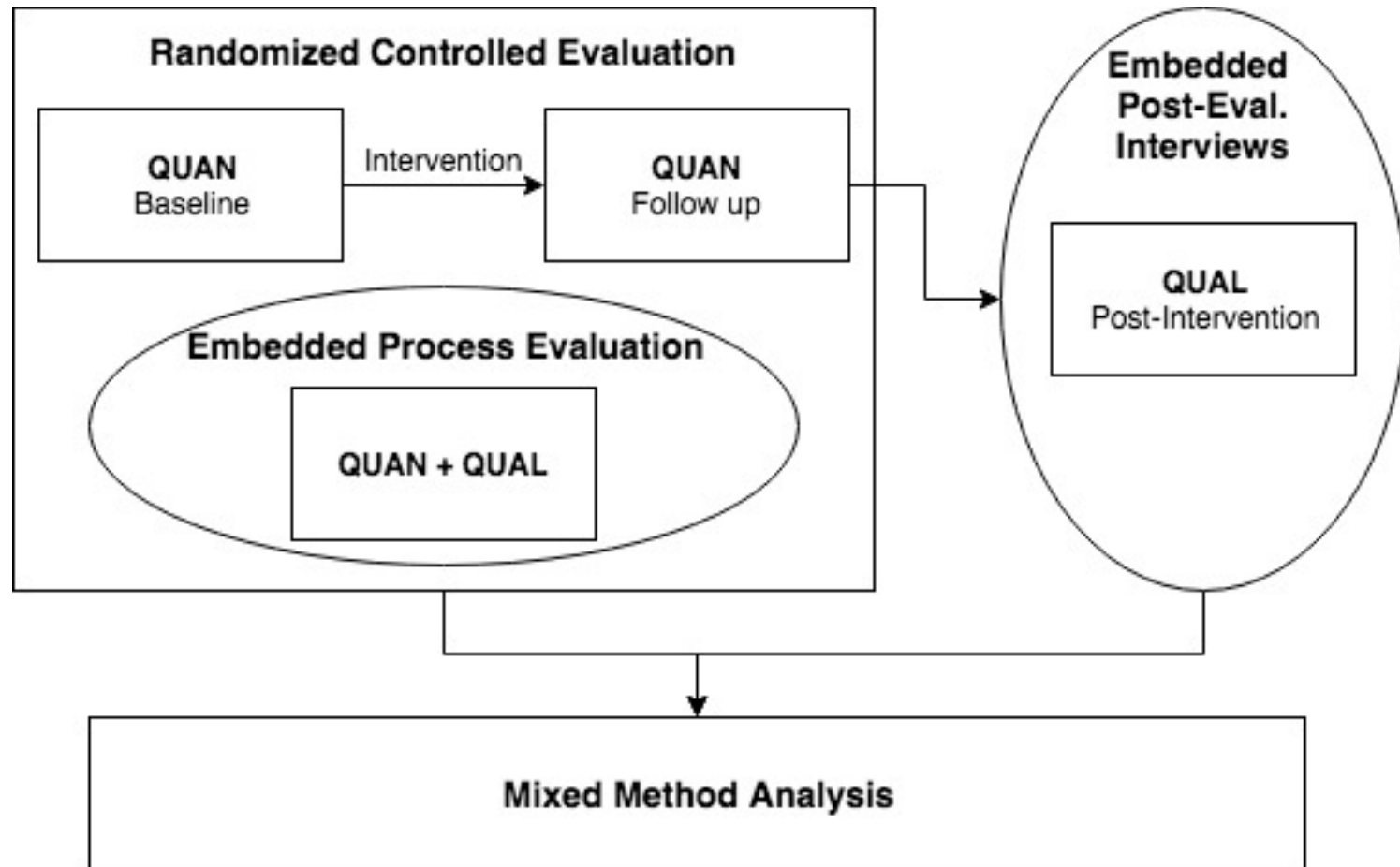
Feasibility: Qualitative and Integrated Analysis

- Drawbacks and recommendations
 - Disruptive and intrusive
 - Overwhelming
 - Confusing and unclear
 - Technical difficulties
 - Desire for more help with the system

Feasibility: Discussion

- Adjustment and adaptation
- Plug and play likely will not work for ADRD caregivers
 - Need for ongoing consultation and assistance
- Possible that home environments and caregiving situations are simply too diverse to accommodate this technology
- Quan results largely derive from 6-month checklists

Study Design



Interim: Baseline Characteristics

| Demographic | Caregiver | Care Recipient |
|--|---------------|----------------|
| Female, <i>n</i> (%) | 103 (78.0%) | 69 (52.7%) |
| Age, years, M ± SD | 61.71 ± 12.09 | 77.88 ± 9.23 |
| Caucasian, <i>n</i> (%) | 128 (97.0%) | 123 (93.2%) |
| Married, <i>n</i> (%) | 109 (82.6%) | 80 (60.6%) |
| Living children, M ± SD | 2.06 ± 1.71 | 2.91 ± 2.17 |
| BA or higher, <i>n</i> (%) | 88 (66.7%) | 62 (47.0%) |
| Employed, <i>n</i> (%) | 54 (40.9%) | |
| Income ≥ \$80,000, <i>n</i> (%) | 54 (40.9%) | |
| Providing care, months, M ± SD | 34.19 ± 23.99 | |
| Spouse of care recipient, <i>n</i> (%) | 65 (49.2%) | |
| Income ≥ \$30,000, <i>n</i> (%) | | 78 (59.1%) |
| Lives with caregiver, <i>n</i> (%) | | 74 (56.1%) |
| Medicaid, <i>n</i> (%) | | 26 (19.8%) |

Interim: Data Analysis

- Repeated ANOVAs: At the 6-month follow-up family caregivers randomly assigned to RAM would experience:
 - Significant ($p < .05$) improvements in self-efficacy and sense of competence; and
 - Reductions in caregiver distress (subjective stress, depressive symptoms).
- Open-ended 6-month RAM Checklist data ($N = 49$) were coded using Braun and Clarke's (2006) six steps of thematic analysis
 - What made a difference in how RAM was received by participants?
- Mixed methods analysis: Post-hoc, 3-way repeated measures ANOVAs

Interim: Quantitative Results

| | Baseline | | | | 6 months | | | |
|----------------|-----------|-------|---------|-------|-----------|-------|---------|-------|
| | Treatment | | Control | | Treatment | | Control | |
| Outcomes | Mean | SD | Mean | SD | Mean | SD | Mean | SD |
| SSOC | 24.17 | 5.18 | 24.26 | 5.46 | 23.33 | 5.58 | 23.73 | 5.85 |
| Self-Efficacy | 27.94 | 6.00 | 27.62 | 6.01 | 28.39 | 7.38 | 27.59 | 7.06 |
| Burden | 37.59 | 13.26 | 37.01 | 15.24 | 40.40 | 16.15 | 40.93 | 18.54 |
| Role Captivity | 6.13 | 2.30 | 6.35 | 2.51 | 6.74 | 2.65 | 6.56 | 2.69 |
| Role Overload | 7.95 | 2.66 | 7.41 | 2.67 | 7.51 | 2.80 | 7.42 | 2.74 |
| CES-D | 33.01 | 12.74 | 32.51 | 11.21 | 38.90 | 16.92 | 35.95 | 13.46 |

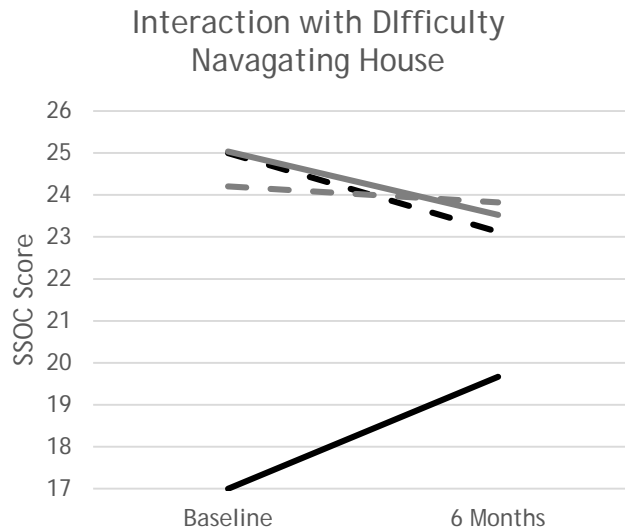
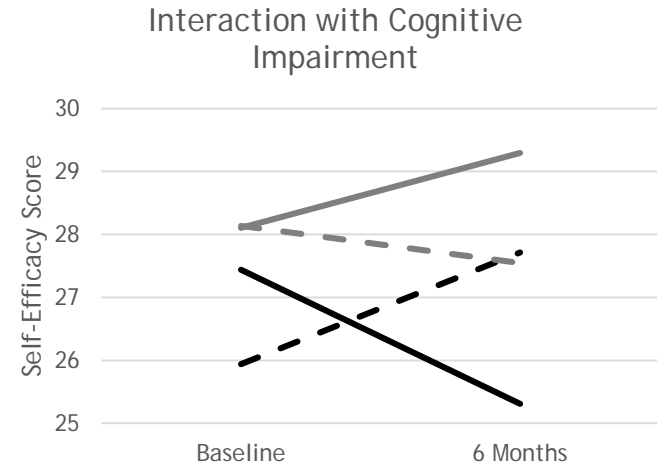
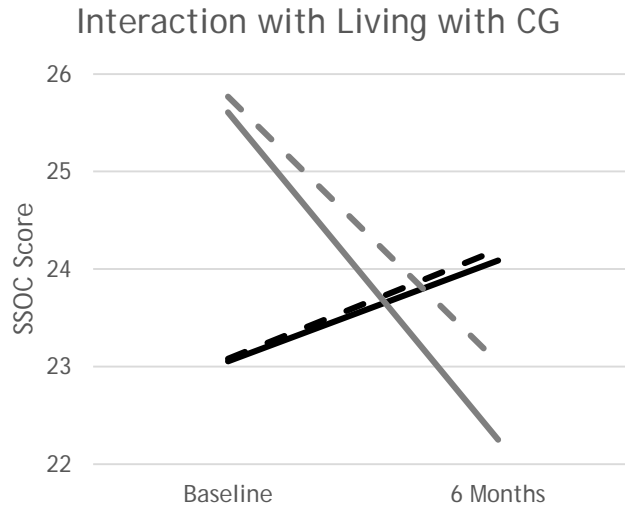
Interim: Qualitative Results

| Qualitative Theme | Qualitative Variable |
|-----------------------------------|---|
| Time constraints and stress level | Work status |
| Comfort with technology | Not available |
| Care recipient behavior | ADL/IADLs Memory & behavior problems Wandering |
| Dementia status | Cognitive impairment ADLs, IADLs Memory & behavior problems |
| Living arrangement | Care recipient, caregiver live together |

Interim: Qualitative Results

| Qualitative Theme | Representative Quotes |
|-----------------------------------|--|
| Time constraints and stress level | <i>I have not received [RAM] alerts and have not been able to go into the data. In all honesty I have been consumed with some significant health issues with my mother over the past 6 months along with making sure [care recipient's] needs are met. (wife, age not disclosed)</i> |
| Comfort with technology | <i>impossible to use for those who are not computer savvy (husband, age 88)</i> <i>It's easy to use (if you have some familiarity with technology)...I like that I can check the system on any internet connected device (daughter, age 61)</i> |
| Care recipient behavior | <i>When I see that she is opening and closing her refrigerator more often in the system, I've learned it's probably time to go grocery shopping with her again (daughter, age 61).</i> |
| Dementia status | <i>[Care recipient] has not progressed in the disease to require the monitoring. (wife, age 81)</i> <i>Emergency alerts are tricky with a person as far into dementia as my mother was & we never found a use for them. (daughter, age 54)</i> |
| Living arrangement | <i>I didn't use it, simply because it was time consuming to handle what I was up to, and since I lived with Mother, I felt like I know what I needed to know about her movements. (daughter, age 54)</i> |

Interim: Mixed Method Results



- Treatment - High Moderator
- Control - High Moderator
- Treatment - Low Moderator
- Control - Low Moderator

Interim: Discussion

- Weighing the costs of a preliminary effectiveness analysis
 - Threats to power and Type I/Type II errors (i.e., fishing/p-hacking; Counsell et al., 2017)
 - Societal urgency: The needs of families and key stakeholders
 - As Berridge (2018) notes in a recent policy analysis of Medicaid (which has recently emerged as the largest third-party payer of RAM technologies), “Decisions about Medicaid reimbursement of technologies that have the potential to dramatically alter the way older adults receive supportive services are being made without research on their use, social and ethical implications, or outcomes” (p. 1).

Interim: Discussion

- Scientific “lessons learned”
 - The need to intend and adequately power for such analyses at the outset
 - Allows for the required statistical flexibility to respond to the rapid development and evolution of smart home technologies often marketed to families
 - Appropriate conceptualizations/theoretical frameworks
 - Stress Process Model
 - Person-Environment Fit

Interim: Limitations

- Blinding did not occur in this study
 - Budget limitations
- Among those LTFU ($n = 5$), there were significant differences on two covariates.
- Not all caregivers provided 6-month open-ended responses.
- Open-ended responses were generally brief and imprecise, thus limiting the depth and richness of available qualitative data.
- Comfort with technology was not assessed quantitatively.



Questions & Discussion

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