

Aligning Technology with Dementia Caregiver Needs

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AIMS

- What do dementia caregivers need as it pertains to technological support?
- Technology as intervention in dementia care: Our remote activity monitoring study as example
- How can technology advance the state of dementia care science?

HOW CAN TECHNOLOGY SUPPORT DEMENTIA CARE? (Lorenz et al., 2019, from Gaugler et al., 2021)

- Memory support
- Treatment
- Safety
- Security (most common)
- Training
- Care delivery
- Social interaction
- Other functions

TECHNOLOGY CHALLENGES IN DEMENTIA CARE (from Brookman et al, 2023)

- Complexity of technology
- Familiarity/comfort with technology
- Memory concerns with remembering/using technology
- “Troubleshooting” technological concerns (Sriram et al., 2022; Gaugler et al., 2016)
- Whether technology can adapt to the dynamism/long-term trajectory of dementia (Jennings et al., 2017)
- Whether popular technology marketed to the general population meets the needs of people living with dementia and their care partners

DEMENTIA CAREGIVERS' PERCEPTIONS OF TECHNOLOGY AND CARE (Brookman et al, 2023)

- Widespread need for care recipients
 - Functional independence
 - Social interaction
 - Management of behaviors
- Experience with technology use
 - Low rates of use
 - Skepticism
 - Adaptation of existing technologies
- Caregivers' design solutions
 - Technology to facilitate casual/regular social engagement
 - Customizable technology that has familiar interfaces
 - Maintain personhood/identity with connection to life stories/relationships (Garlinghouse et al., 2018)

IMPLICATIONS OF TECHNOLOGY SOLUTIONS IN THE DEMENTIA CARE CONTEXT (Demiris, 2021)

- Caregiving burden/strain
- Consent and acceptance
- Health equity
 - Gaugler, McCarron and Mitchell (2019): Concerns regarding:
 - Cost of precision medicine and insurance coverage;
 - Lack of alignment with cultural norms;
 - Fraught relationships between communities, health professionals, and researchers;
 - Data ownership and privacy;
 - Trade-off between knowing risk and treatment benefit

REMOTE ACTIVITY MONITORING FOR PEOPLE LIVING WITH DEMENTIA AND THEIR CAREGIVERS

- To describe the effects of remote activity monitoring technology on the well-being of:
 - Family caregivers of people living with dementia
 - People living with dementia at home

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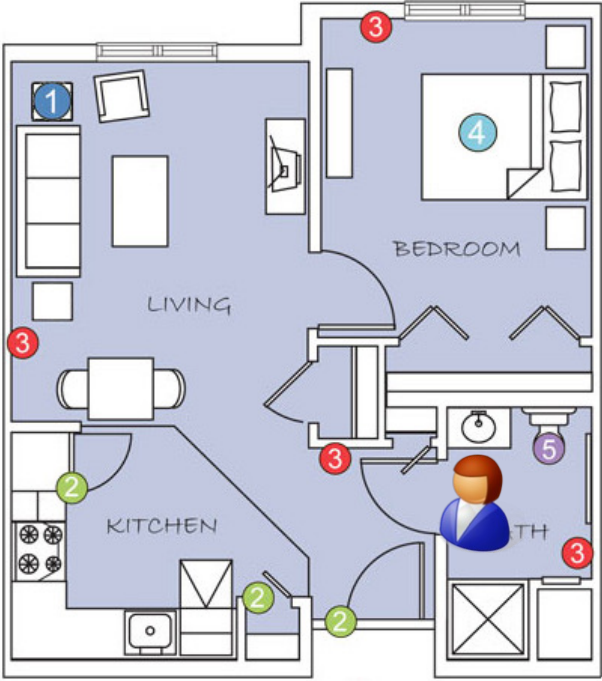
- 1 Call Pendant
- 2 Contact Sensor
- 3 Motion Sensor
- 4 Bed Sensor
- 5 Toilet Sensor
- 6 I'm O.K. Button



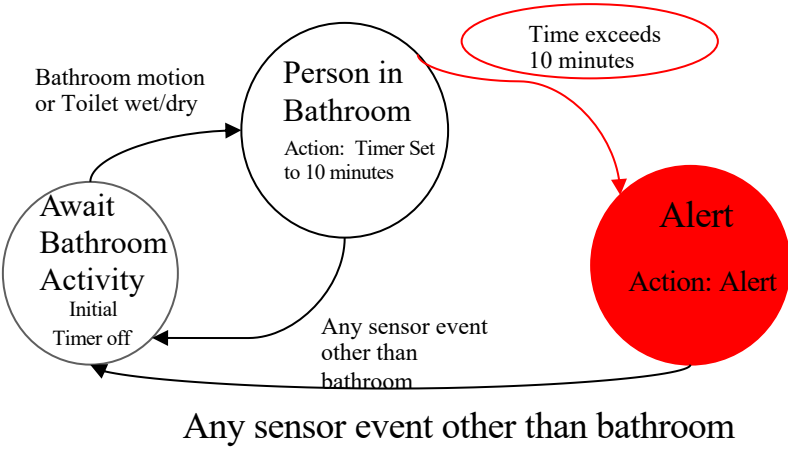
•The combined sensors look for Activities of Daily Living

•If the system does not detect the expected routine it sends an alert call to a list of responders

EXAMPLE ALERT



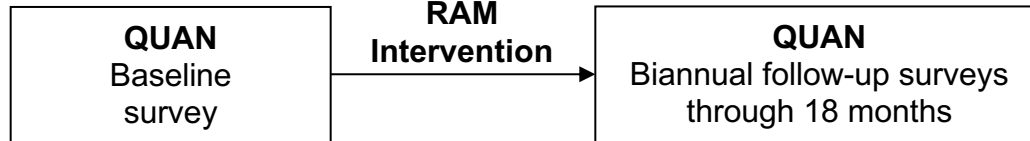
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Randomized Controlled Evaluation

Procedure

1. Baseline interview
2. Random assignment (88 intervention, 91 control)
3. Biannual follow-up over 18 months
4. Key outcomes: caregiver efficacy, competence, and distress



Embedded Process Evaluation

qual + quan

Biannual open-ended and close-ended survey items over 18 months to examine RAM system utility

**Stratified
purposive
sample:
Perceived utility
(n = 15 increase)
(n = 15 decrease)**

Embedded Post-Evaluation Interviews

QUAL
Semi-structured
interviews to identify
modifiers of RAM
benefit

Mixed Methods Analysis

Integration of findings from randomized controlled evaluation with embedded components to examine points of convergence or divergence as to how and why RAM system is effective

Caregiver

Care recipient

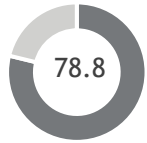
Relationship

Living Arrangement

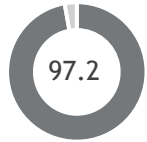
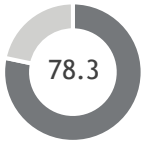
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Age

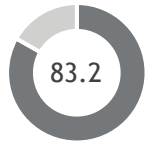
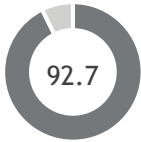
78.3



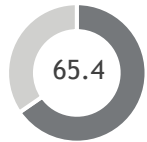
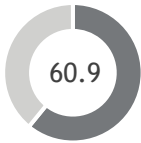
Female



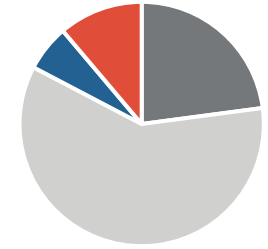
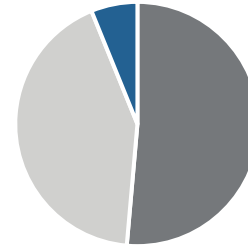
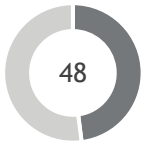
White



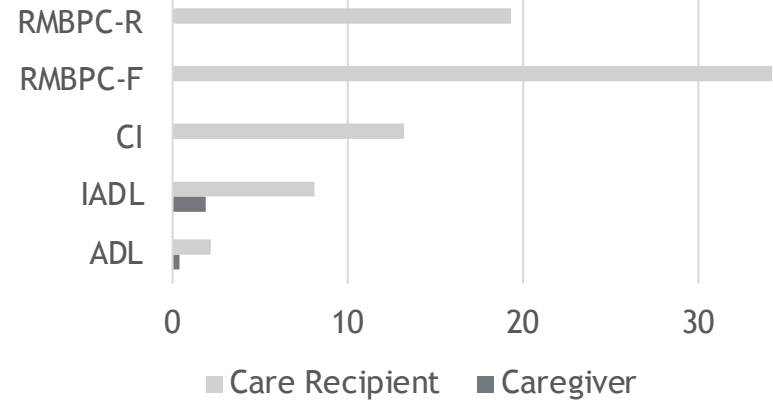
Married



Graduated college



■ Spouse ■ Child ■ Other ■ Alone ■ Caregiver ■



THEMATIC ANALYSIS

Question: What changed over time that impacted perceptions of and engagement with the RAM?



1. **Adjustment period**
2. Level of ongoing technological support
3. Care recipient reaction over time
4. **ADRD progression**
5. Medical insights and tracking
6. **Shifting life contexts**
7. Gaining comfort and trust

ADJUSTMENT PERIOD

- “some of the charts were difficult to use at first but I learned how to read them.” Maria (61y, F)
- "I tried to use it in the beginning but found it too difficult so I gave up.... I felt like I should have been able to figure it out and when I couldn't, I stopped asking for help." Janice (51y, F)

ADRD PROGRESSION

- “the alerts are the most useful tool in the [RAM] system for me right now because my mother's Alzheimer's has advanced so that I have to be at her home every day... The day-to-day monitoring from my computer isn't as crucial but the alerts let me know about the situations of concern.” Maria (61y, F)
- “His disease progressed in a way where that wasn't particularly helpful. He's not a wanderer. He still has really good judgment. He's declined, but in ways different than I anticipated when I enrolled [in the study].” Heidi (67y, F)

SHIFTING LIFE CONTEXTS

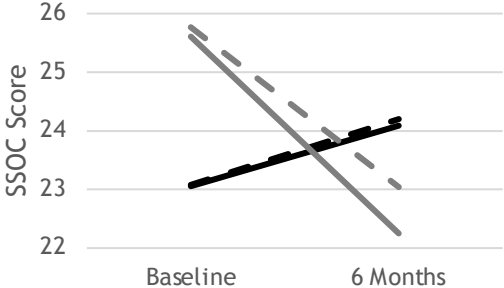
- “I was laid-off from my job in September 2016, and I currently work part-time from home, so I am caregiving almost 100% of the time now. So, I have not used [the RAM] at all.” Terry (60y, F)
- “We’d go up to the lake three, four days at a time. We’d go out [doing] other things. I had a heart attack. I was in the hospital for six days. There was never any kind of reaction from that system. We never heard anything, never called, never anything.” Dorothy (88y, F)

QUANTITATIVE ANALYSIS

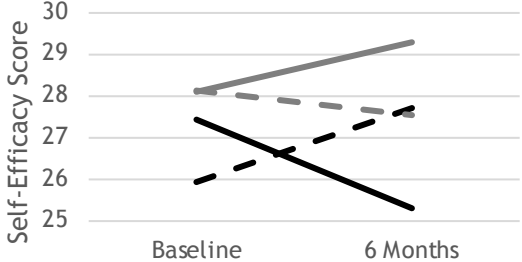
- Latent growth curve model
 - No association between treatment and role overload, role captivity, or depressive symptoms ($p > .05$)
 - No significant interaction between treatment and falls, wandering, emergency room admissions, difficulty navigating the home, or living with caregiver ($p > .05$)

SIX MONTH OUTCOMES

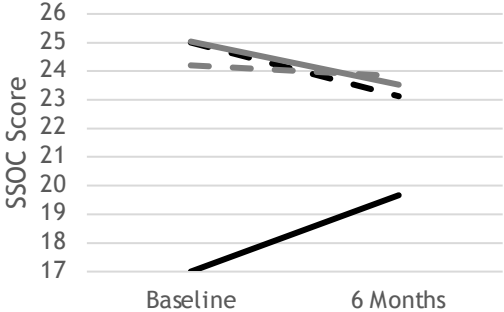
Interaction with Living with CG



Interaction with Cognitive Impairment



Interaction with Difficulty Navigating House



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

	RAM Intervention	Control	p-value
<i>Falls</i>			
Baseline (T1), n (%)	47 (53.4%)	52 (57.1%)	0.615
6 months (T2), n (%)	38 (45.8%)	45 (52.3%)	0.217
12 months (T3), n (%)	31 (39.7%)	39 (46.4%)	0.498
18 months (T4), n (%)	36 (46.8%)	50 (61.7%)	0.037
<i>Wandering</i>			
Baseline (T1), n (%)	26 (29.6%)	15 (16.5%)	0.037
6 months (T2), n (%)	21 (25.3%)	12 (14.0%)	0.051
12 months (T3), n (%)	20 (25.6%)	19 (22.6%)	0.650
18 months (T4), n (%)	23 (29.9%)	15 (18.5%)	0.086
<i>Nursing home admission</i>			
Baseline (T1), n (%)	3 (3.4%)	2 (2.2%)	0.623
6 months (T2), n (%)	4 (4.8%)	3 (3.5%)	0.664
12 months (T3), n (%)	10 (12.8%)	3 (3.6%)	0.030
18 months (T4), n (%)	4 (5.2%)	6 (7.4%)	0.395
<i>Other residential admission</i>			
Baseline (T1), n (%)	3 (3.4%)	6 (6.6%)	0.330
6 months (T2), n (%)	9 (10.8%)	13 (15.1%)	0.409
12 months (T3), n (%)	8 (10.3%)	14 (16.7%)	0.234
18 months (T4), n (%)	9 (11.7%)	8 (9.9%)	0.713
<i>Hospitalization</i>			
Baseline (T1), n (%)	18 (20.5%)	12 (13.2%)	0.193
6 months (T2), n (%)	11 (13.3%)	13 (15.1%)	0.729
12 months (T3), n (%)	7 (9.0%)	6 (7.1%)	0.668
18 months (T4), n (%)	4 (5.2%)	11 (13.6%)	0.072
<i>Emergency room visit</i>			
Baseline (T1), n (%)	35 (39.8%)	24 (26.4%)	0.057
6 months (T2), n (%)	20 (24.1%)	23 (26.7%)	0.693
12 months (T3), n (%)	9 (11.5%)	19 (22.6%)	0.062
18 months (T4), n (%)	11 (14.3%)	22 (27.2%)	0.047

	Odds Ratio (SE)	95% CI	p-value
Falls	0.48 (.18)	(0.23-1.00)	0.051
Wandering	1.65 (.79)	(0.65-4.22)	0.290
Nursing home admission	1.58 (.71)	(0.65-3.82)	0.314
Other residential care admission	0.73 (.24)	(0.38-1.40)	0.346
Hospitalization	0.77 (.23)	(0.43-1.39)	0.384
Emergency room visit	0.51 (.17)	(0.27-0.97)	0.041

	Quotes
Falls	<p>“I’m sure we prevented falls. It didn’t prevent every single one, but I’m sure that the fact that I got the call, and they were immediate, so I was on the move as soon as the phone rang.” “Mom had a couple of falls where I woke up to the crash. And the phone had not rung.” (Female caregiver, 54 years old)</p> <p>“Because it is so effective in waking up the caregiver at just the right time with just the right amount of time to get to him, that we have—you know, knock on wood—decreased the opportunity for falling <u>tremendously</u>. If there was something with too much of a lag time, that’s when falls occur is, you know, by the time the caregiver gets there and he’s on the floor.” (Female caregiver, 51 years old)</p> <p>“And the falling and things like that. Yeah, that’s so important, the wandering thing. And it did save me a couple of nights that it was kind of—you get scared and then—but you know, I was [warned] and [had] enough time to fix the problem.” (Female caregiver, 78 years old)</p>
Emergency Room visit	<p>“There was one time that I didn’t hear her fall, and she had fallen. So I was alerted immediately. So that could have been bad.” “Because when she fell, she could automatically, if she had her old button, she could automatically have been sent to the ER rather than alerting me immediately to know about it.” (Female caregiver, 55 years old)</p>

DISCUSSION

- Caregivers utilized and integrated RAM technology into their caregiving routine in a variety of ways
- Caregivers need for RAM technology varied by time due to family context and ADRD severity
- Researchers and providers should consider professional care management alongside passive monitoring systems for best results

DISCUSSION

- The findings imply that this technology may prevent some adverse health events for people living with dementia in the community
 - The ongoing, unobtrusive monitoring and system alerts of RAM may have resulted in caregivers identifying activity or the lack thereof that may have prevented falls and wandering events
 - In turn, emergency room use among persons with dementia may have been avoided
 - Although other trials have reported null or non-significant findings, the 18-month follow-up period may have allowed us to identify the influence of RAM on health service use or other events that are more likely to occur over time
- Limitations
 - Unrepresentative sample
 - Researcher blinding was not possible
 - Fidelity/internal validity
 - Differential loss to follow up (12%) over study

CONCLUSION

- Technology solutions that:
 - Supplement extensive, unpaid assistance from family members and others; and
 - Prevent or delay the onset of negative health events could address dementia care challenges
 - Need to identify tools to effectively tailor/match caregivers and people living with dementia with the *right* technology
 - See ATTILA trial

NIA AD/ADRD RESEARCH IMPLEMENTATION MILESTONES: DEMENTIA CARE (13.A-13.R)

- [Care & Caregiving: Technology-based dementia assessment and care \(Milestone 13.I\)](#)
 - Achieved (2020-2023)
 - [Collaborative Aging Research Using Technology \(CART\)](#)
 - [Artificial Intelligence and Technology Collaboratories for Aging Research \(AITC; a2 Collective\)](#) (Li et al., 2024)

2023 NATIONAL RESEARCH SUMMIT ON CARE, SERVICES, AND SUPPORT FOR PEOPLE WITH DEMENTIA AND THEIR CARE PARTNERS AND CAREGIVERS

- **New Milestone: Health IT Consequences and Disparities**
 - Support research on how health information technology affects care access, quality, and costs for persons living with AD/ADRD and their care partners, including populations disproportionately affected by AD/ADRD and/or underrepresented in research.
 - **Success Criteria:** Support at least 4 new research projects or activities that do one or more of the following:
 - Examine how persons living with AD/ADRD and their care partners interact with health information technology and the associated benefits and consequences.
 - Identify and describe the factors driving disparities in health information technology accessibility, availability, and utilization, including the importance of user-friendly design of patient portals to engage patients and care partners and telehealth to monitor care coordination.
 - Examine variabilities in health information technology access and develop strategies to address disparities in accessibility and use across settings, including home and community, clinical, and residential care settings.

MY THOUGHTS

- How can technology be used to fill the gaps in dementia care science?
 - Fidelity assessment
 - Person-centered measurement
 - Pragmatism/implementation
 - Inclusivity
 - Mechanisms: Moving beyond feasibility/acceptability
 - Specifying and scaling multiple components
- *The Gerontologist* special issue on AI: Thoughts?

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- **Families and LTC Projects**
- **Center for Healthy Aging and Innovation**

REMOTE ACTIVITY MONITORING PUBLICATIONS

- Gaugler, J. E., Rosebush, C. A., Zmora, R., & Albers, E. A. (2022). Outcomes of remote activity monitoring for persons living with dementia over an 18-month period. *Journal of the American Geriatrics Society*, 70(8), 2439–2442. <https://doi.org/10.1111/jgs.17839>
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