Aligning Technology with Dementia Caregiver Needs

Joseph E. Gaugler, PhD
GRANT SUPPORT

• National Institute on Aging: (R21 AG060419, 2018-2022, PI; R43 AG049548, 2016-2017, Co-I; K02 AG029480, 2008-2013, PI)

• Agency for Healthcare Research & Quality (R18 HS022836, 2014-2020, PI; K18 HS022445, 2013-2016, PI; R03 HS020948, 2012-2014, PI)
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
ACKNOWLEDGMENTS

• Co-authors:
  – Rachel Zmora, MPH, PhD, Boston University
  – Lauren L. Mitchell, PhD, Emmanuel College
  – Jessica Finlay, PhD, University of Michigan
  – Christina Rosebush, PhD, MPH, University of Minnesota
  – Colleen M. Peterson, PhD, University of Michigan
  – Manka Nkimbeng, PhD, MPH, RN, University of Minnesota
  – Zachary G. Baker, PhD, University of Minnesota
  – Elle Albers, MPH, University of Minnesota

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• ClinicalTrials.gov NCT03665909, retrospectively registered on 11/09/2018
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

Person in Bathroom
Action: Timer Set to 10 minutes

Await Bathroom Activity
Initial Timer off

Bathroom motion or Toilet wet/dry

Person in Bathroom
Action: Timer Set to 10 minutes

Time exceeds 10 minutes

Alert
Action: Alert

Any sensor event other than bathroom

Any sensor event other than bathroom
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

Embedded Post-Evaluation Interviews
QUAL
Semi-structured interviews to identify modifiers of RAM benefit

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

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

QUAN
Baseline survey

RAM Intervention

QUAN
Biannual follow-up surveys through 18 months

QUAN
Baseline survey

School of Public Health
University of Minnesota

Center for Healthy Aging and Innovation
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)
“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)
“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**

S Soc Score

Baseline | 6 Months

**Interaction with Cognitive Impairment**

Self-Efficacy Score

Baseline | 6 Months

**Interaction with Difficulty Navigating House**

S Soc Score

Baseline | 6 Months

Legend:
- Treatment - High Moderator
- Control - High Moderator
- Treatment - Low Moderator
- Control - Low Moderator
<table>
<thead>
<tr>
<th></th>
<th>RAM Intervention</th>
<th>Control</th>
<th>p-value</th>
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</thead>
<tbody>
<tr>
<td><strong>Falls</strong></td>
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<tr>
<td>Baseline (T1), n (%)</td>
<td>47 (53.4%)</td>
<td>52 (57.1%)</td>
<td>0.615</td>
</tr>
<tr>
<td>6 months (T2), n (%)</td>
<td>38 (45.8%)</td>
<td>45 (52.3%)</td>
<td>0.217</td>
</tr>
<tr>
<td>12 months (T3), n (%)</td>
<td>31 (39.7%)</td>
<td>39 (46.4%)</td>
<td>0.498</td>
</tr>
<tr>
<td>18 months (T4), n (%)</td>
<td>36 (46.8%)</td>
<td>50 (61.7%)</td>
<td>0.037</td>
</tr>
<tr>
<td><strong>Wandering</strong></td>
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<tr>
<td>Baseline (T1), n (%)</td>
<td>26 (29.6%)</td>
<td>15 (16.5%)</td>
<td>0.037</td>
</tr>
<tr>
<td>6 months (T2), n (%)</td>
<td>21 (25.3%)</td>
<td>12 (14.0%)</td>
<td>0.051</td>
</tr>
<tr>
<td>12 months (T3), n (%)</td>
<td>20 (25.6%)</td>
<td>19 (22.6%)</td>
<td>0.650</td>
</tr>
<tr>
<td>18 months (T4), n (%)</td>
<td>23 (29.9%)</td>
<td>15 (18.5%)</td>
<td>0.086</td>
</tr>
<tr>
<td><strong>Nursing home admission</strong></td>
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<tr>
<td>Baseline (T1), n (%)</td>
<td>3 (3.4%)</td>
<td>2 (2.2%)</td>
<td>0.623</td>
</tr>
<tr>
<td>6 months (T2), n (%)</td>
<td>4 (4.8%)</td>
<td>3 (3.5%)</td>
<td>0.664</td>
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<tr>
<td>12 months (T3), n (%)</td>
<td>10 (12.8%)</td>
<td>3 (3.6%)</td>
<td>0.030</td>
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<tr>
<td>18 months (T4), n (%)</td>
<td>4 (5.2%)</td>
<td>6 (7.4%)</td>
<td>0.395</td>
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<tr>
<td><strong>Other residential admission</strong></td>
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<tr>
<td>Baseline (T1), n (%)</td>
<td>3 (3.4%)</td>
<td>6 (6.6%)</td>
<td>0.330</td>
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<tr>
<td>6 months (T2), n (%)</td>
<td>9 (10.8%)</td>
<td>13 (15.1%)</td>
<td>0.409</td>
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<tr>
<td>12 months (T3), n (%)</td>
<td>8 (10.3%)</td>
<td>14 (16.7%)</td>
<td>0.234</td>
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<tr>
<td>18 months (T4), n (%)</td>
<td>9 (11.7%)</td>
<td>8 (9.9%)</td>
<td>0.713</td>
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<tr>
<td><strong>Hospitalization</strong></td>
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<tr>
<td>Baseline (T1), n (%)</td>
<td>18 (20.5%)</td>
<td>12 (13.2%)</td>
<td>0.193</td>
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<tr>
<td>6 months (T2), n (%)</td>
<td>11 (13.3%)</td>
<td>13 (15.1%)</td>
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<tr>
<td>12 months (T3), n (%)</td>
<td>7 (9.0%)</td>
<td>6 (7.1%)</td>
<td>0.668</td>
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<tr>
<td>18 months (T4), n (%)</td>
<td>4 (5.2%)</td>
<td>11 (13.6%)</td>
<td>0.072</td>
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<tr>
<td><strong>Emergency room visit</strong></td>
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<tr>
<td>Baseline (T1), n (%)</td>
<td>35 (39.8%)</td>
<td>24 (26.4%)</td>
<td>0.057</td>
</tr>
<tr>
<td>6 months (T2), n (%)</td>
<td>20 (24.1%)</td>
<td>23 (26.7%)</td>
<td>0.693</td>
</tr>
<tr>
<td>12 months (T3), n (%)</td>
<td>9 (11.5%)</td>
<td>19 (22.6%)</td>
<td>0.062</td>
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<tr>
<td>18 months (T4), n (%)</td>
<td>11 (14.3%)</td>
<td>22 (27.2%)</td>
<td>0.047</td>
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<tr>
<td>Event</td>
<td>Odds Ratio (SE)</td>
<td>95% CI</td>
<td>p-value</td>
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<tr>
<td>Falls</td>
<td>0.48 (.18)</td>
<td>(0.23-1.00)</td>
<td>0.051</td>
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<tr>
<td>Wandering</td>
<td>1.65 (.79)</td>
<td>(0.65-4.22)</td>
<td>0.290</td>
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<tr>
<td>Nursing home admission</td>
<td>1.58 (.71)</td>
<td>(0.65-3.82)</td>
<td>0.314</td>
</tr>
<tr>
<td>Other residential care admission</td>
<td>0.73 (.24)</td>
<td>(0.38-1.40)</td>
<td>0.346</td>
</tr>
<tr>
<td>Hospitalization</td>
<td>0.77 (.23)</td>
<td>(0.43-1.39)</td>
<td>0.384</td>
</tr>
<tr>
<td>Emergency room visit</td>
<td>0.51 (.17)</td>
<td>(0.27-0.97)</td>
<td>0.041</td>
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<td>Quotes</td>
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<tr>
<td><strong>Falls</strong></td>
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<tr>
<td>“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)</td>
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<td>“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 tremendously. 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)</td>
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<td>“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)</td>
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<tr>
<td><strong>Emergency Room visit</strong></td>
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<tr>
<td>“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)</td>
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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
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

- **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)
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.
• 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?
• Joe Gaugler
  • gaug0015@umn.edu
  • 612-626-2485
• X/Twitter: @umnchai
• LinkedIn: www.linkedin.com/in/jegaugler
• RLK Chair in Aging
• Families and LTC Projects
• Center for Healthy Aging and Innovation
REMOTE ACTIVITY MONITORING PUBLICATIONS


REFERENCES