

National Research Summit on

Care, Services, and Supports for Persons with Dementia and Their Caregivers

Summit Virtual Meeting Series

July 10, July 21, and August 13, 2020

EMERGING TOPICS



National Institute
on Aging



Emerging Topics

Session Moderators



David B. Reuben, MD



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Emotional Functioning in Persons with Dementia and their Care Partners



Joan K. Monin, PhD
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August 13, 2020



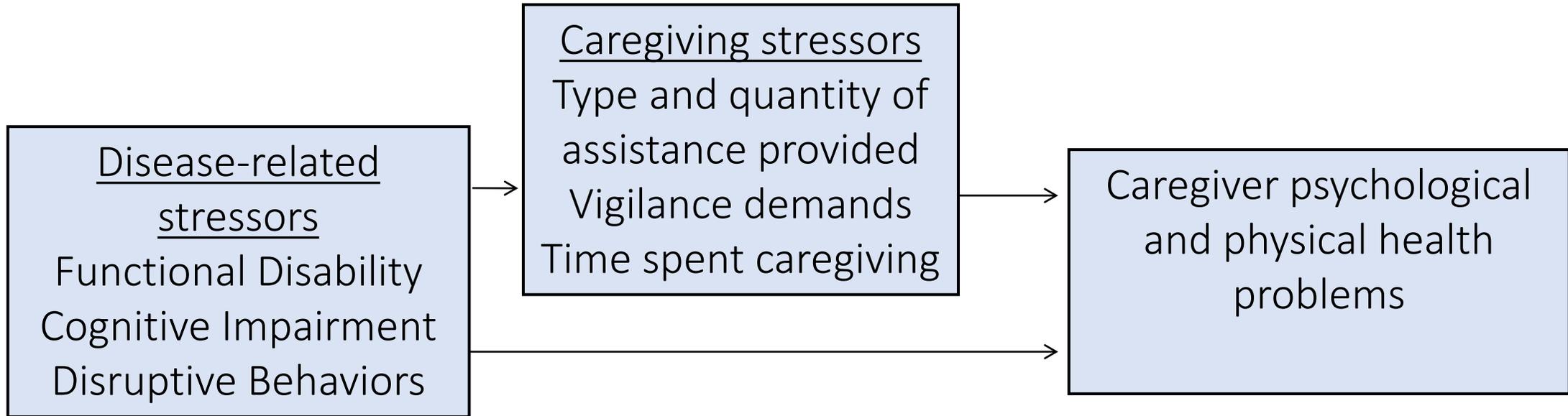
Disclosures

- I am a member of the Design and Statistics Core of the NIA IMPACT Collaboratory.
- I currently receive funding from the NIA (R01AG058565; R21AG055861-01A1; P30 AG21342).

Overview

- Emotional processes that affect the health of persons living with dementia and their care partners
- Individual differences that affect emotions in caregiving
- What this means for interventions
- Future directions

Caregiver stress health models*



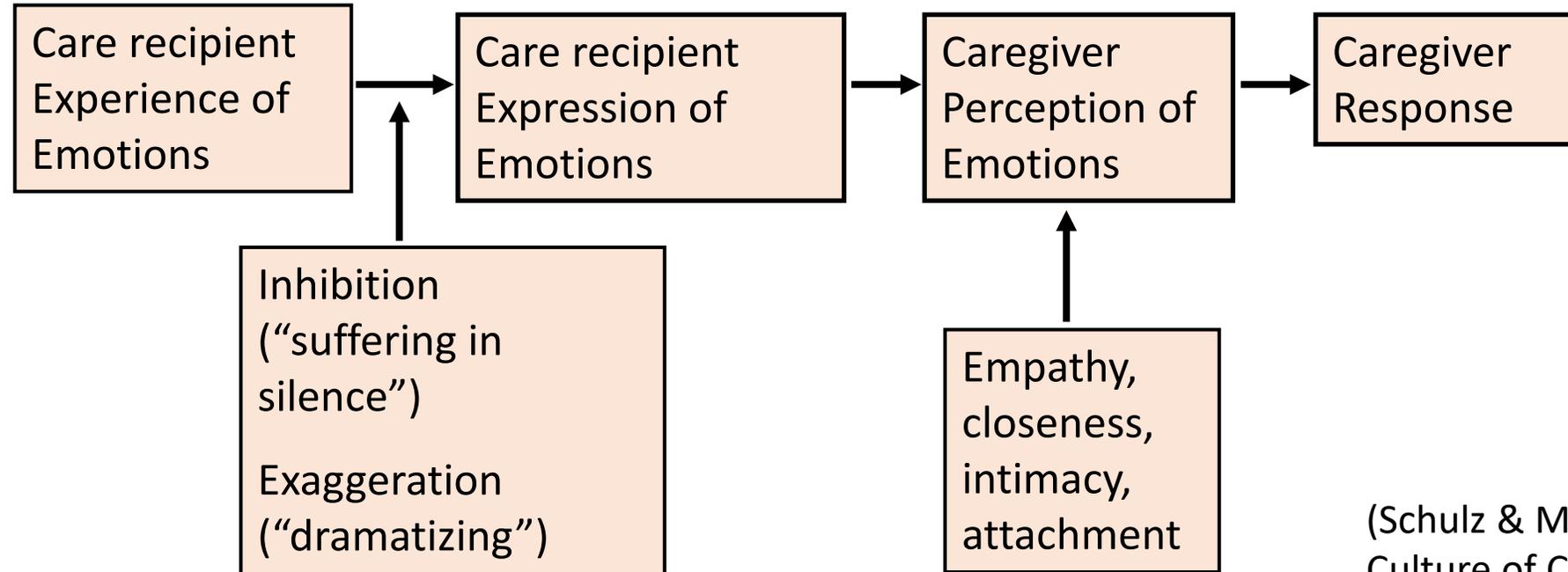
*A simplification of models that have dominated the field (e.g. Pearlin, Mullan, Semple & Skaff, 1990).

What are emotional processes?

- No scientific consensus on the definition of emotion
- Emotion may include thoughts, feelings, and/or behaviors with physiological arousal.
- Degrees of pleasure versus displeasure
- Measures covered here: e.g., depressive symptoms; caregiver burden; self-reported emotions; physiological indicators

(Experts in Emotions Series by June Gruber, 2013, YaleCourses, Youtube)

The experience, expression, and perceptions of emotions in caregiving



(Schulz & Monin, 2018, Culture of Care in Aging)

Negative emotions and health in dementia caregiving

- Perceiving that a person with dementia is **suffering** is associated with poor psychological and physical health for family members (e.g. Monin & Schulz, 2010; Schulz, Beach, Czaja, et al, 2020).
- The experience of **guilt** in caregivers as an outcome separate from burden and depression (Romero-Moreno, Losada, Marquez, et al, 2014).
- Persons living with dementia do not live as long when their caregivers are depressed (Lwi, Ford, Casey, et al., 2017)

Positive emotions and health in dementia caregiving

- Positive and negative emotions have independent effects on caregivers' well-being (e.g. Lawton, Moss, Kleban, et al, 1991; Quinn, Nelis, Martyr, et al, 2019).
- Positive aspects of caregiving (e.g. Tarlow, Wisniewski, Belle, et al., 2004; Quinn & Toms, 2019)
- Positive emotion expression protective in both partners
 - **Love** (e.g. Monin, Schulz, & Feeney, 2015; Gallagher & Beard, 2020)
 - Genuine **smiles** from persons with dementia associated with better caregiver mental health (e.g., Lwi, Casey, Verstaen, et al, 2019)

Individual differences and emotions in dementia caregiving

- Emotional experiences of persons with Alzheimer's disease and **Frontotemporal dementia**; implications for caregivers (e.g., Ascher et al., 2010; Chen et al., 2017)
- **Female** caregivers report more distress than male caregivers (e.g., Pillemer, Davis & Tremont, 2018).
- Cultural/ethnic differences mixed (Janevic & Connell, 2001; Thrush & Hyder, 2014). E.g. Greater **familism** among Latinos, greater **filial obligation** among Asians, more **religious coping** among African Americans.

What this means for interventions

- Focus on emotional experience and expression in caregiving
- Include both the person living with dementia and their primary care partner (and potentially secondary care partners)
- Target and tailor to the needs of different groups and individuals (e.g. gender, culture, relationship type, stage and type of dementia, personality)

Existing effective interventions that address emotions

- **Mindfulness-based approaches:** moderate to large effects on burden and depression for care partners (e.g. Collins & Kishita, 2019); some evidence for quality of life for persons with dementia (e.g., Russell-Williams, et al., 2018)
- **Physical activity:** most targeted toward caregivers only; significant effects on distress, quality of life, positive affect; need more high quality trials (Lambert et al., 2016); home-based physical activity interventions effective in delaying cognitive decline but also have psychological effects for persons with dementia (Almeida et al. 2019)
- **Cognitive behavioral therapy:** strong effects in reducing depression in care partners (Kwon et al., 2017)

Promising interventions that address emotions

Music and memory for persons living with dementia

(Thomas, Baier, Kosar, et al., 2017)

Positive affect training for care partners

(Verstaen, Moskowitz, Snowberg, et al, 2018)

Emerging Research Relating to Emotional Function: Future Directions

- Obtain better emotion measures from persons living with dementia
- Address the emotional needs of persons living with dementia
- Develop interventions that address close relationship processes
- Collect/record information about caregivers in the healthcare system so we can conduct embedded pragmatic clinical trials with dyads



Technological Reserve in Persons with Dementia

The Promise and Pitfalls of Smart Systems for Health, Well-Being, and
Independence

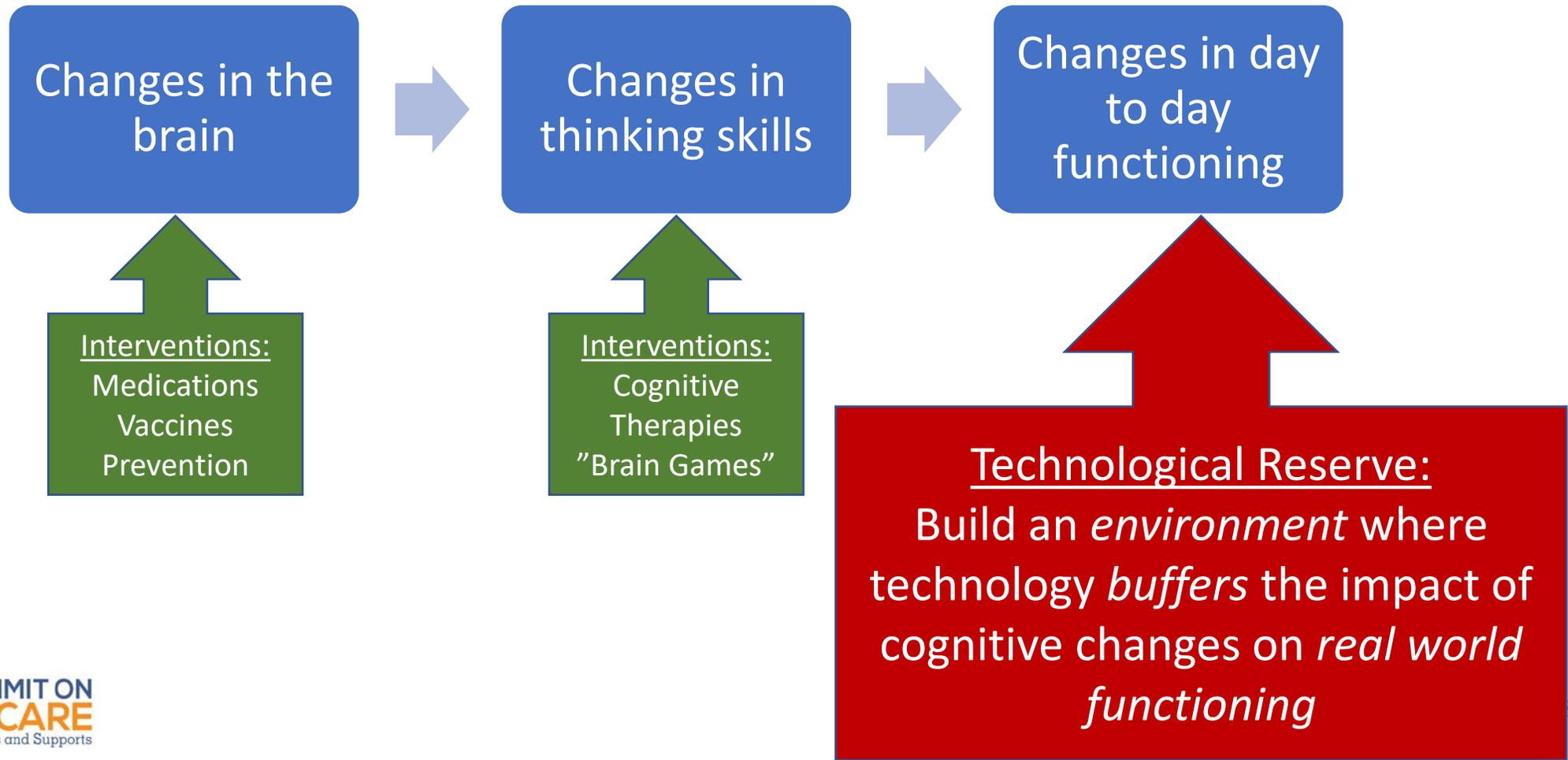
Jared F. Bengel, Ph.D., ABPP-CN



Disclosures

- Support received from National Institutes of Aging (AG053161)
- Material support (smartphones) received from Microsoft corporation, 2017
- Primary collaborator: Michael Scullin, Ph.D., Baylor University

Technological Reserve: The Idea



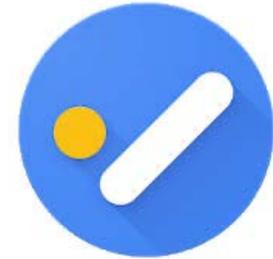
The Promise of Technology: *As a Cognitive Prosthetic*

- Reminders on the smartphone

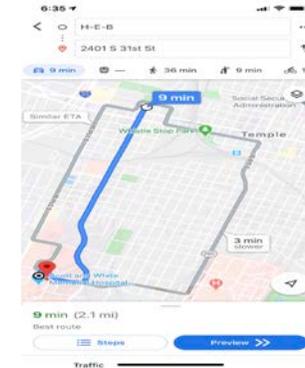


- GPS for directions

Microsoft

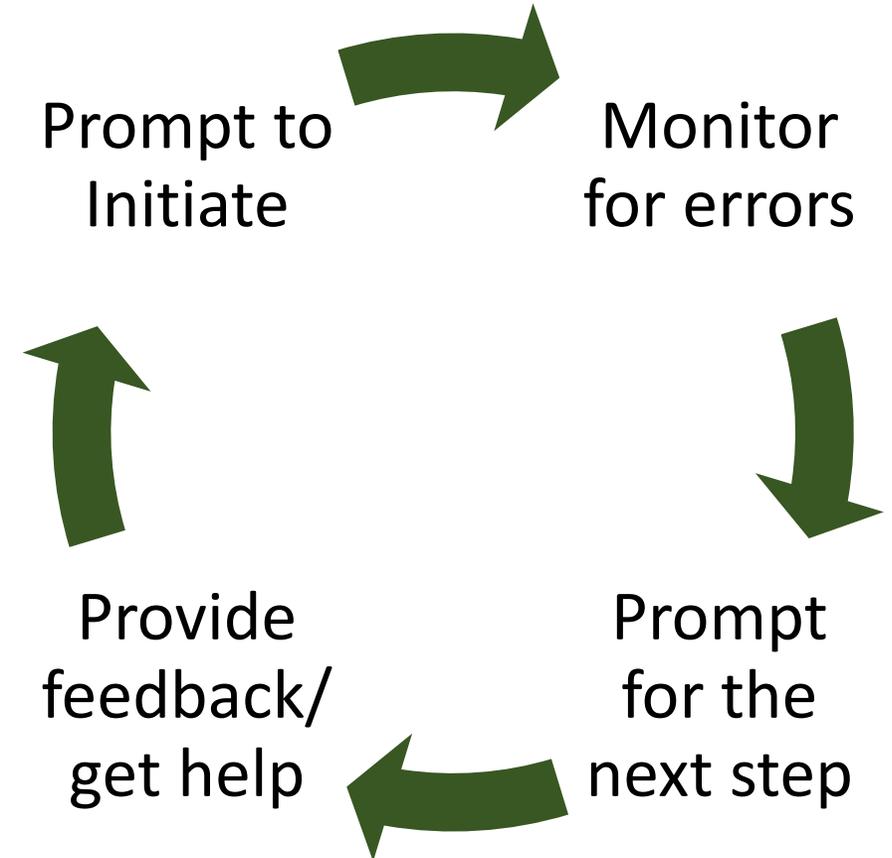


- Augmentative communication



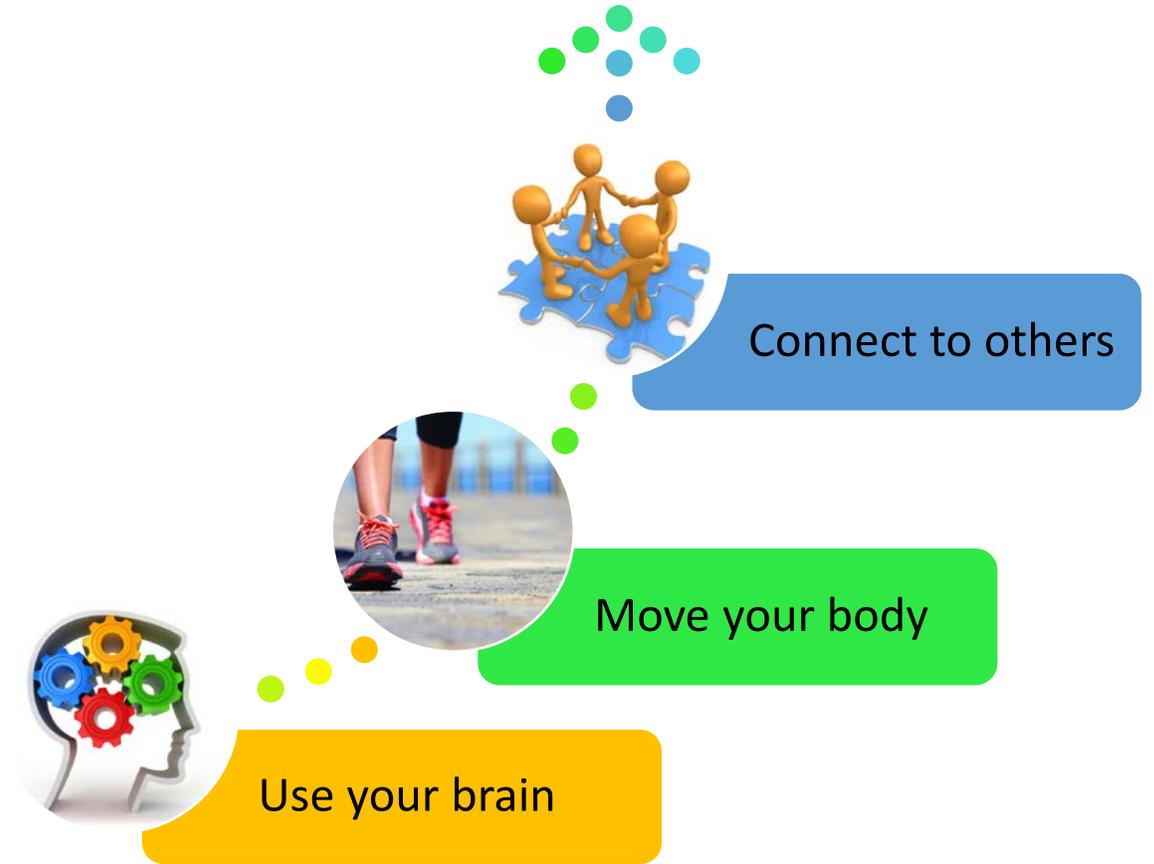
The Promise of Technology: *For Independence and Safety*

- “Smart home” prompting/ monitoring systems
- Self-driving car/ Ride sharing apps
- GPS tracking



The Promise of Technology: *For Well-Being and Social Connectedness*

- Social apps/networks to reduce isolation, provide training.
- Exercise/mindfulness reminders and tracking
- Platforms to promote communication with treatment team/avoid hospitalizations



The Promise of Technology: *For Systems and Communities*

- Avoiding/detecting medication errors or non-compliance
- Facilitating communication amongst providers/community helpers/ care partners
- Supporting independence and safety in the broader community



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Show me the data!

- Numerous survey studies, pilot/case studies, small clinical trials, and even products already being marketed
- Just a few of several high quality projects/centers:



Collaborative Aging Research
Using Technology

Large controlled trials are generally lacking



Assistive technology for memory support in dementia (Review)

Van der Roest HG, Wenborn J, Pastink C, Dröes RM, Orrell M

Main results

We identified no studies which met the inclusion criteria.

Authors' conclusions

This review highlights the current lack of high-quality evidence to determine whether AT is effective in supporting people with dementia to manage their memory problems.



Pitfalls in Technological Interventions

- Do those in need have adequate *access to a tech enabled environment?*
- Do those at risk have access to high speed internet/cellular service?
- Who will provide tech support? Does it place more burden on care partners?
- How do racial, ethnic, and socio-economic disparities impact availability and utilization of technologies?

Pitfalls in Technological Interventions (cont.)

- Can we build *stable and usable platforms* to develop these interventions?
- The life of research: multiple years developing pilot data, then large scale multi-year study.
- The life of technology: innovate, new release, new feature, new design.
- The life of a clinician/ person with dementia/ care partner: use what is available, which differs person to person

Pitfalls in Technological Interventions (cont.)

- How do we address and mitigate privacy risks?
- Can we truly “de-identify” large or home monitoring data sets?
- How do we explain data risks to stakeholders?
- How do we weigh benefits of monitoring vs. risks to stakeholders?

Pitfalls in Technological Interventions (cont.)

- How does technological literacy impact the effectiveness of interventions?
- How does pre-impairment familiarity with technology impact usability?
- Can we promote tech literacy early in disease course? Does it impact outcomes?
- How are cohorts changing with regards to tech literacy?

The Path Towards *Technological Reserve*:

- *Understand, promote, and improve* the tech environment, especially in diverse populations
- *Collaborate* with PLWD, care partners, and technology experts to develop usable, researchable platforms
- *Develop secure and ethical approaches* to data collection, maintenance, and explanations to stakeholders
- *Understand PLWD and care partner factors* that impact technology use: the right intervention, for the right person, at the right time, for the right symptom.

References/More Reading

- Articles:

- Bengtson, J. F., Dinh, K. L., Logue, E., Phenis, R., Dasse, M. N., & Scullin, M. K. (2020). The smartphone in the memory clinic: A study of patient and care partner's utilisation habits. *Neuropsychological rehabilitation*, 30(1), 101-115.
- Raghunath, N., Dahmen, J., Brown, K., Cook, D., & Schmitter-Edgecombe, M. (2019). Creating a digital memory notebook application for individuals with mild cognitive impairment to support everyday functioning. *Disability and Rehabilitation: Assistive Technology*, 1-11.
- Van der Roest, H. G., Wenborn, J., Pastink, C., Dröes, R. M., & Orrell, M. (2017). Assistive technology for memory support in dementia. *Cochrane database of systematic reviews*, (6).

- Labs:

- Centers for Advanced Studies in Adaptive Systems: <http://casas.wsu.edu>
- Center for Research and Education on Aging and Technology Enhancement: <https://create-center.ahs.illinois.edu>
- Project MARIO: <http://www.mario-project.eu/portal/>
- Collaborative Aging Research Using Technology: <https://www.ohsu.edu/collaborative-aging-research-using-technology>



Identification at Preclinical Stages of Dementia

Christine K. Cassel, MD

University of California, San Francisco

August 13, 2020



Disclosures

- Medical Advisor to Honor, Inc. (home care)
- Medical Advisor to Wellsheet, Inc (data analytics)
- Board Member, Greenwall Foundation (bioethics)
- Geriatrician, Bioethicist and Caregiver

Early Diagnosis is Now Possible

- How to define pre “clinical”? From whose perspective is it valuable?
- At what cost?
- What therapeutic implications?
- What impact on our lives?

Effects of Information: Topics for Research

- On patients
- On caregivers
- On clinicians
- On communities

- How are these related?

What do we know about stigma?

- What can we do about it?
- A role for activism or education?
- What is the role of research?
- From Why Survive to The Soul of Care

The “pre-caregiver”

- What research is needed?
- Preparing for the age of biomarkers and prevention therapies

*Largent, A, Karlawish, J. Preclinical Alzheimer Disease and the Dawn of the Pre-Caregiver, JAMA 2019.

How does “ethics” help?

- Advance care planning
 - Clinical decision making
 - Participation in research
 - Disclosure
-
- Where are the experts?

Emerging Topics Panelists



Venoreen Browne-Boatswain



Michael R. Belleville