What practice effects can tell us about diagnosis, prognosis, treatment recommendations, and cognitive resilience in late life cognitive disorders

DATE: SEPT 27, 2023 PRESENTED BY: KEVIN DUFF, PHD, ABPP-CN

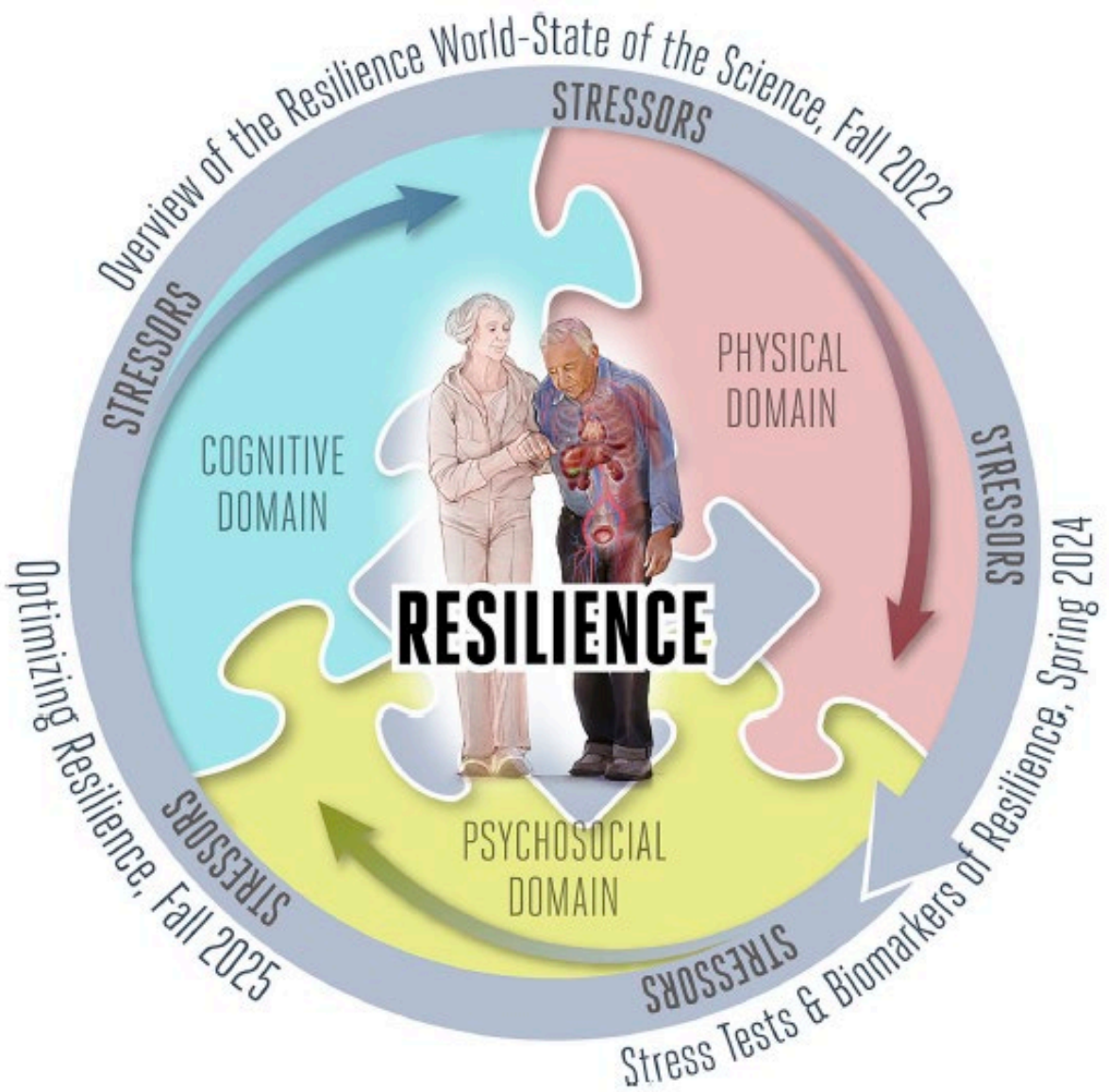
Disclosures

- NIH funding as PI or Co-I (P30AG066518, R01AG075959, R01AG073261, K01AG073578, K01AG075166, R01MH132218)

- Clinical trials as Co-I or rater (VIVA-MIND with Vivoryon Therapeutics N.V.; AHEAD with Eiasi)

Objectives

- Introduce concept of practice effects and how its calculated
- Instruct on value of practice effects in understanding the diagnosis, prognosis, treatment recommendations, and cognitive resiliency in older patients
- Demonstrate these points through a case example



Resilience within the Cognitive Domain

- Cognitive Reserve: better-than-expected cognitive functioning for age or for age-related brain changes
  - Proxy: educational/ occupational attainment
- Brain maintenance: relative absence of "normal" age-related brain changes
  - Proxy: MRI/PET/spectroscopy/etc.
- Interplay of genetic and environmental factors that reduce impact of perturbation on cognition

Abadir et al., 2023

Can studies of people with Alzheimer's disease who do better than expected contribute to an understanding of resilience?

Abadir et al., 2023

Can studies of people with Alzheimer's disease who do better than expected contribute to an understanding of resilience?

Can studies of people with AD, MCI, other neurological diseases, and even cognitively intact older adults who do better than expected contribute to an understanding of resilience?


Tacoma
Yakima
WASHINGTON
Mount
Hood
Vancouver
Portland
Hillsboro
Salem
OREGON
Eugene
Bend
Mount Hood, OR
Copyright Sperling's BestPlaces

Case Presentation

- 78 yo WWF
  - 14 yrs education, retired bookkeeper
  - Widowed x 5 yrs, lives alone, IADLs independent
  - HTN, T2DM, osteoarthritis, depression
  - Gradually worsening memory x 2 yrs
  - MoCA = 22/30 (1/5 recall)
  - Dx of MCI? Referral to neuropsych? Order MRI of brain.
- MRI appt 2 weeks later
  - mild diffuse cerebral volume loss, mild nonspecific white matter hyperintensities
  - MoCA = 26/30 (4/5 recall)
  - No dx of MCI? Referral to neuropsych!

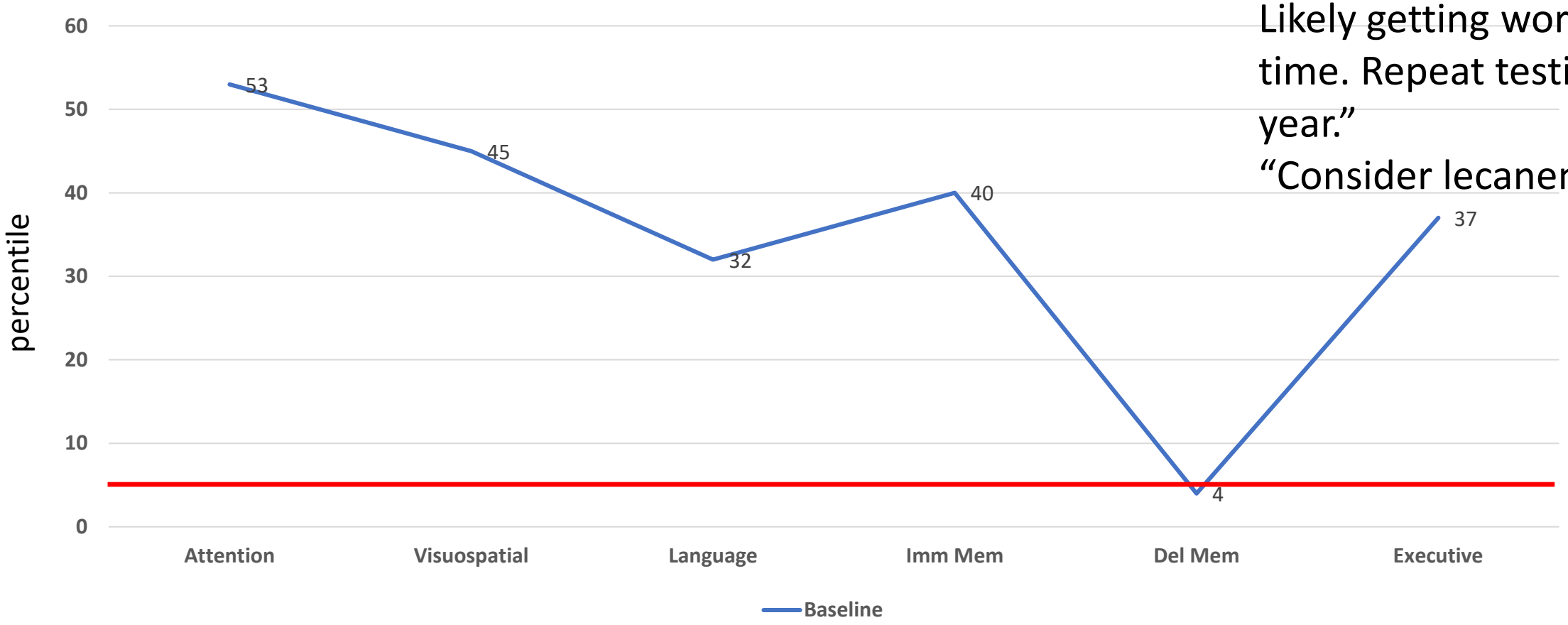
Case Presentation

NP evaluation:

"Intact in all cognitive domains, except delayed memory."

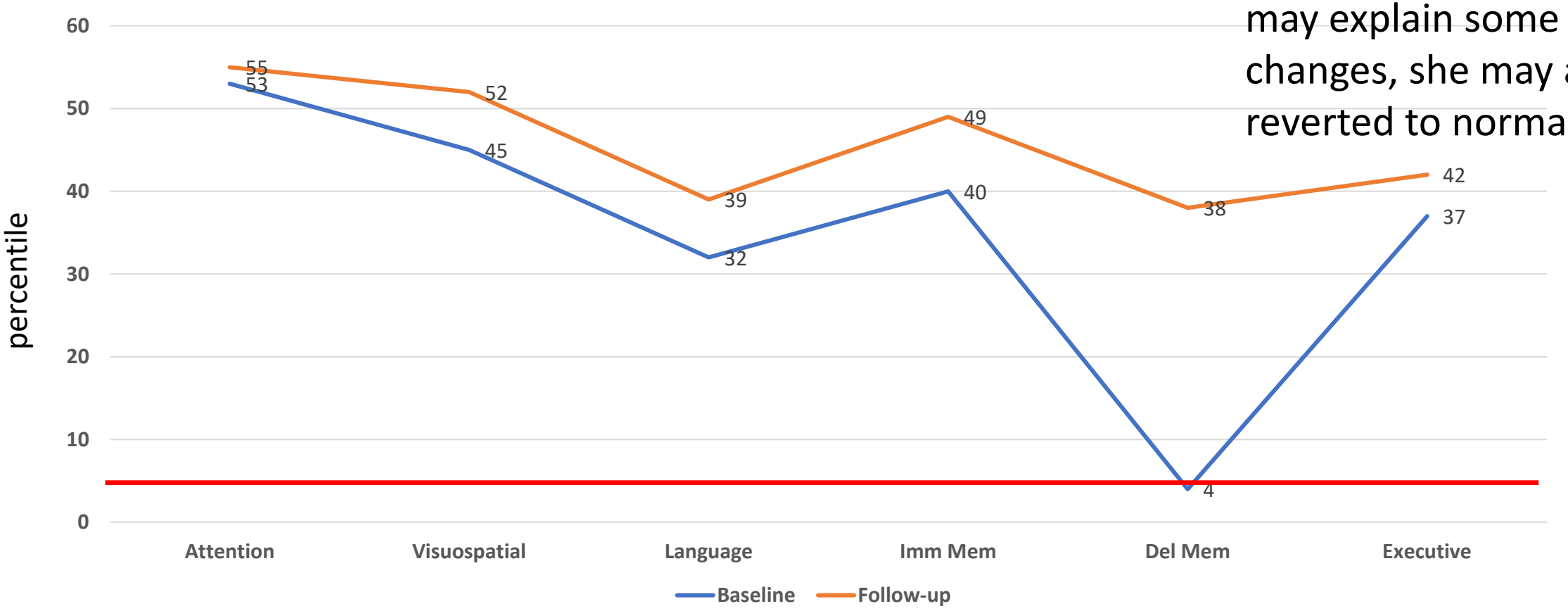
"Likely amnestic MCI. Likely due to Alzheimer's disease. Likely getting worse over time. Repeat testing in one year."

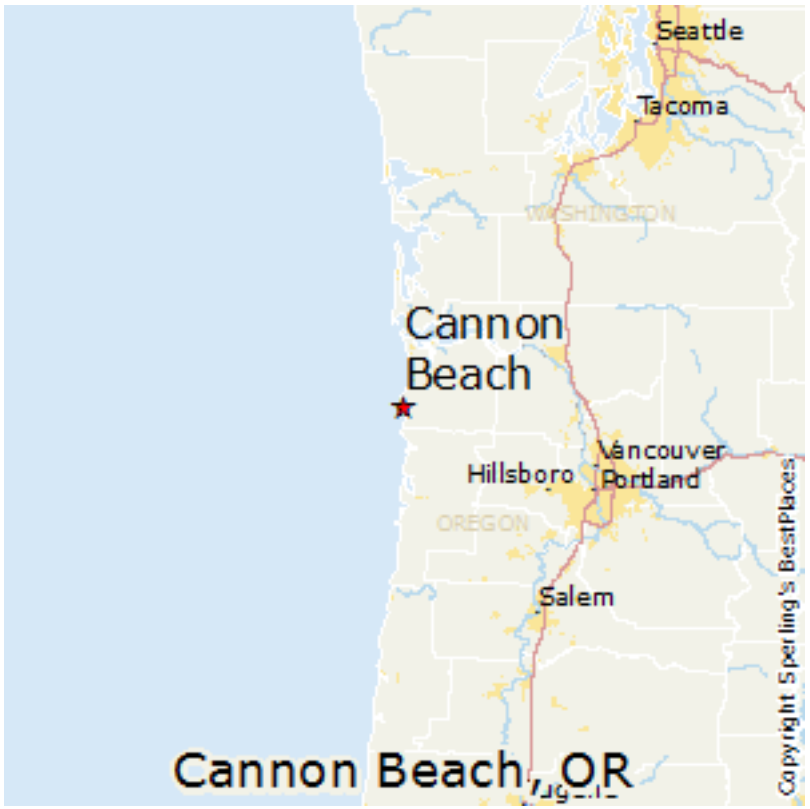
"Consider lecanemab."



Case Presentation

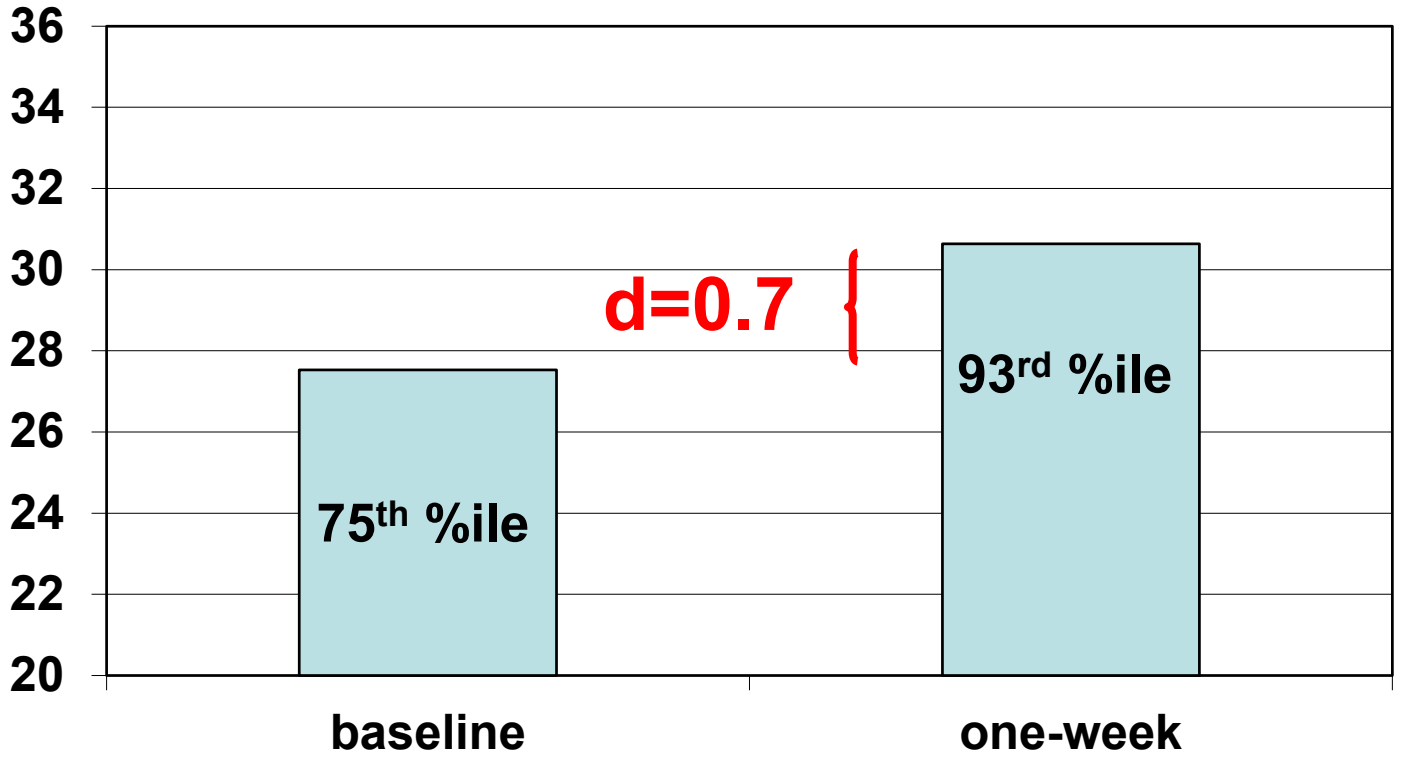
Follow-up NP evaluation:
"Improvements in all cognitive domains, but especially delayed memory."
"Although practice effects may explain some of these changes, she may also have reverted to normal."




Seattle
Tacoma
WASHINGTON
Cannon
Beach
Vancouver
Hillsboro
Portland
OREGON
Salem
Cannon Beach, OR
Copyright Sperling's BestPlaces

Practice effects (PE)

- Improvements in cognitive test performance due to repeated evaluation with the same/similar test materials
- Due to declarative and procedural memory
- Traditionally viewed as source of **error**
- May be a marker of cognitive reserve/plasticity/resiliency



HVLT-R Total Recall in healthy elders

Hammers et al., 2021

Calculating PE

Delay Memory: 73 → 95

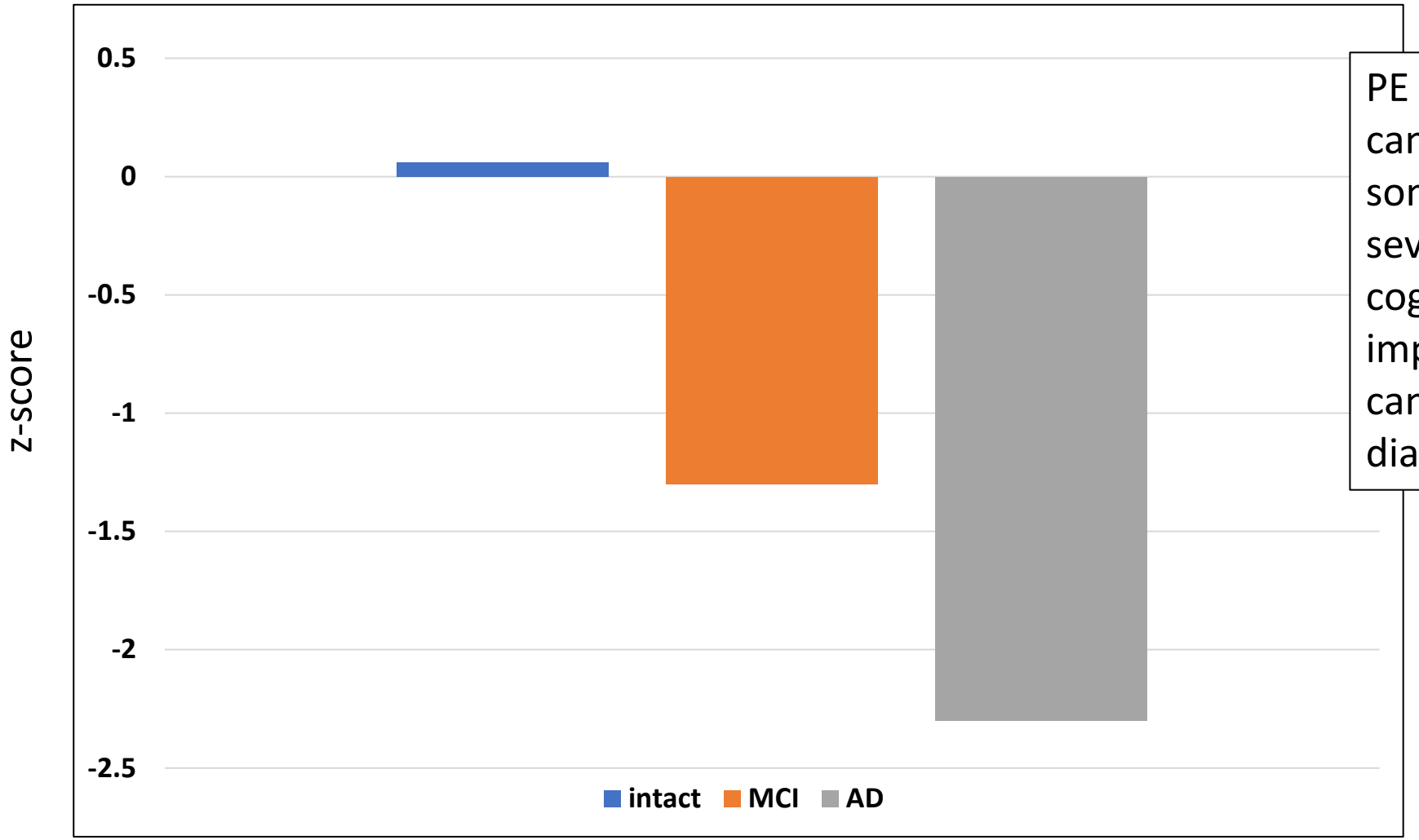
- Simple difference = T2 – T1 or Ratio = T2/T1
  - Easiest, but doesn't correct for expected PE, test-retest reliability, regression to the mean, or baseline score, so not sure if it's clinically meaningful
  - 95 – 73 = 22, ?
  - 95/73 = 30% improvement, ?
- Standardized Regression-Based = $(T2_{OBS} – T2_{PRED})/SEE$
  - Even more challenging, but does correct for all relevant variables
  - Tends to be most sensitive
  - $T2_{PRED}$=82.4; (95 – 82.4)/11.5 = z = 1.1, improved more than 86% of comp group
  - Similar to "Expected Recovery Differential" approach from Dr. Whitson

Duff, 2012
Duff et al., 2017

PE: Nuisance or Informative Marker of Cognitive Resilience?

Reference et al., 2021

PE inform diagnosis

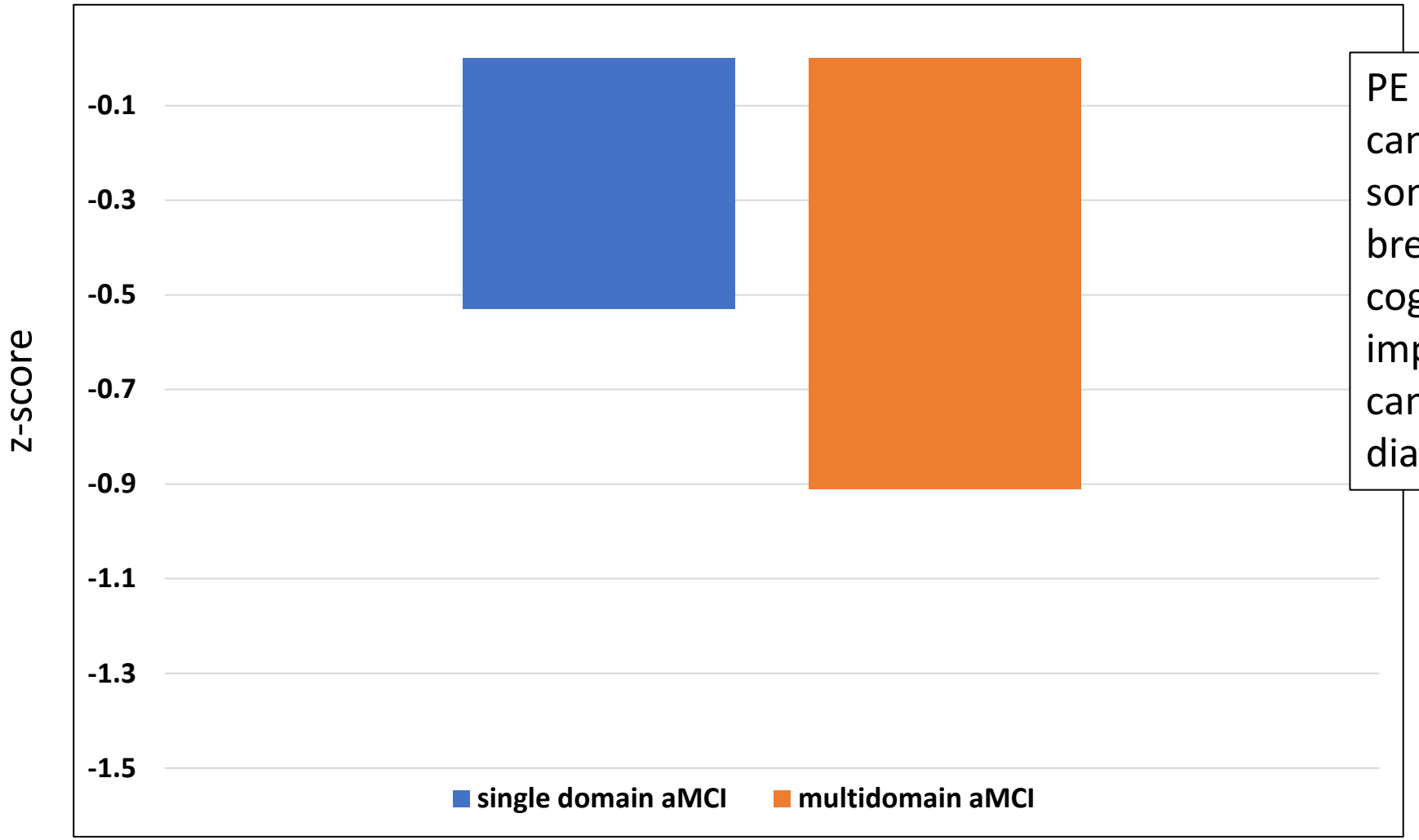


PE across one week can tell us something about the severity of the cognitive impairment, which can inform the diagnosis

APPE
Amyloid Positivity & Practice Effects

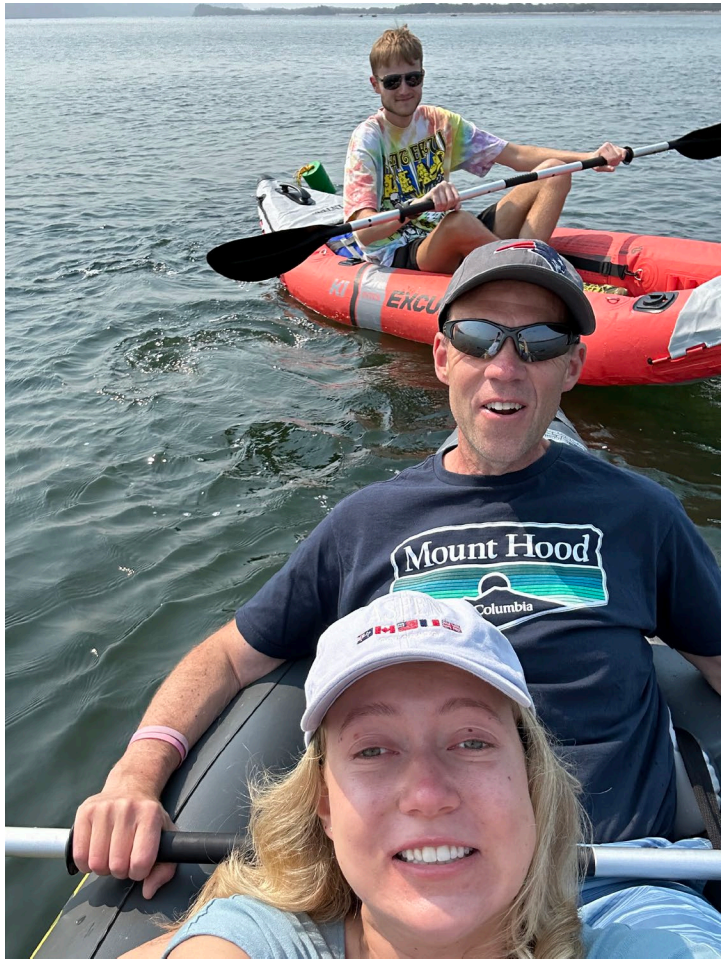
NIA R01: Duff & Hoffman (PIs)

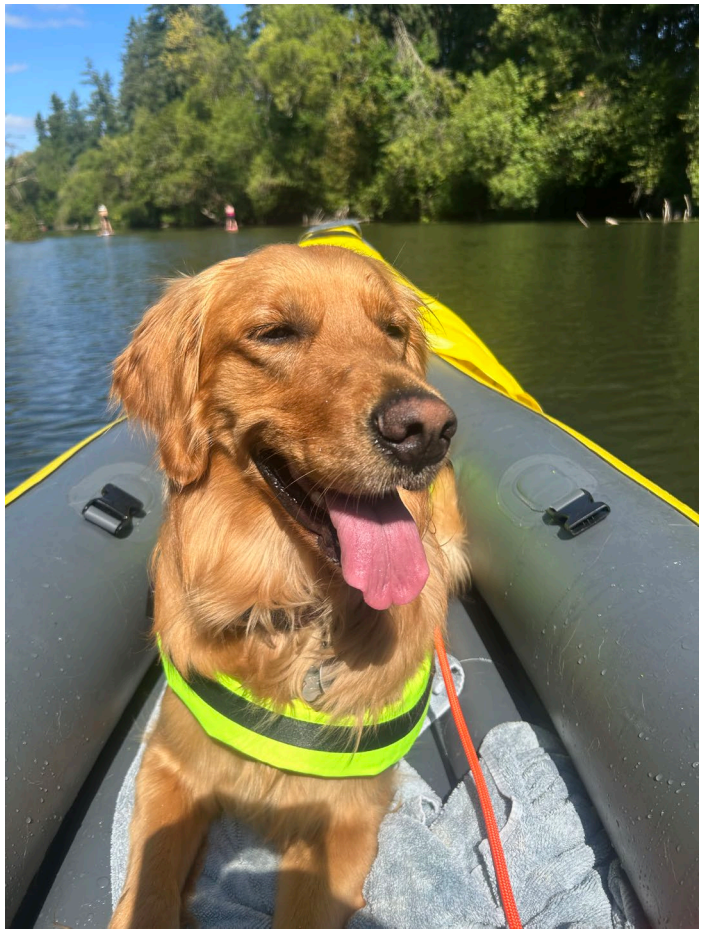
PE inform diagnosis



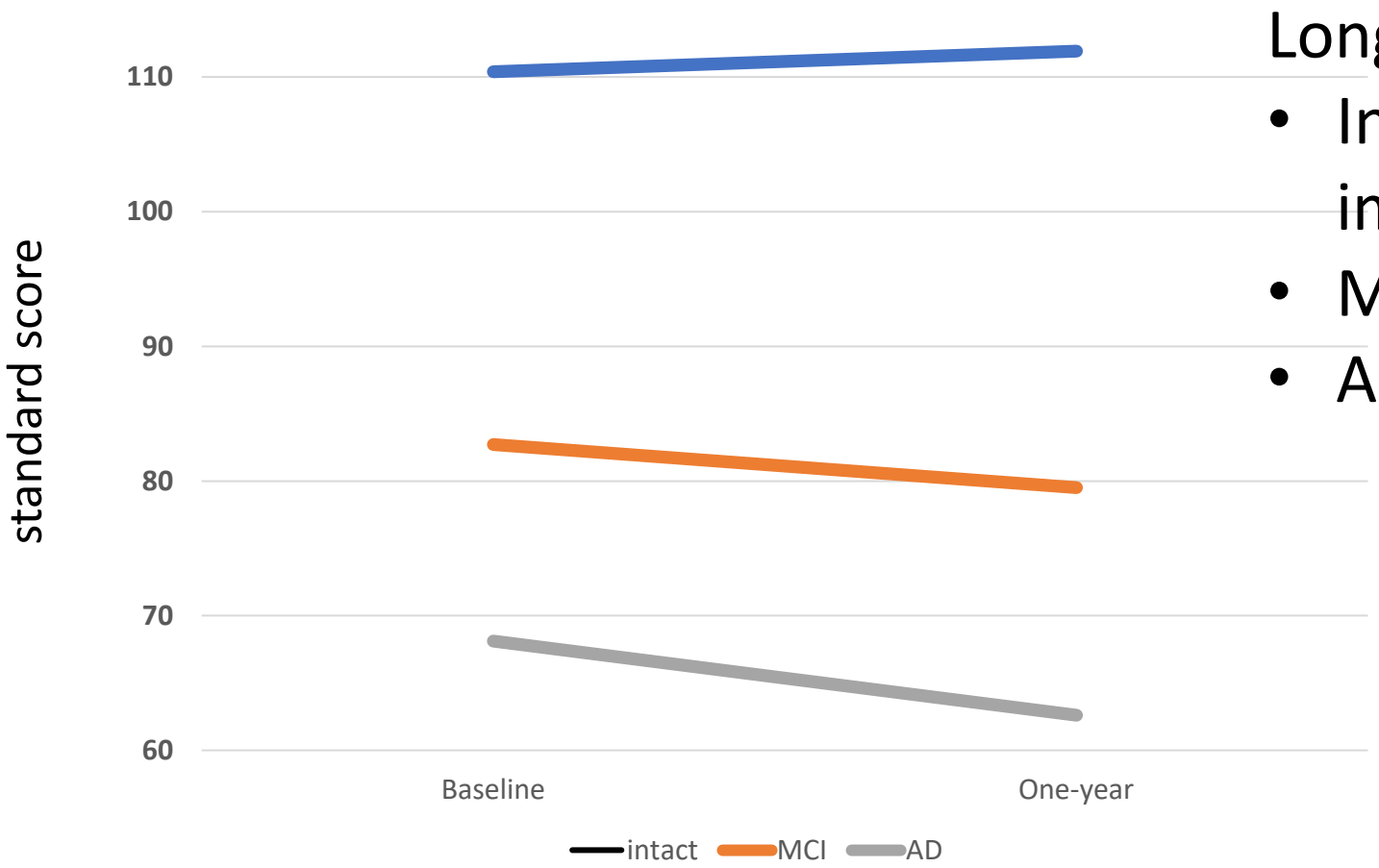
PE across one week can tell us something about the breadth of the cognitive impairment, which can also inform the diagnosis

NIA R01: Duff (PI)
Pilot work funded by CoA


Mount Hood
Columbia



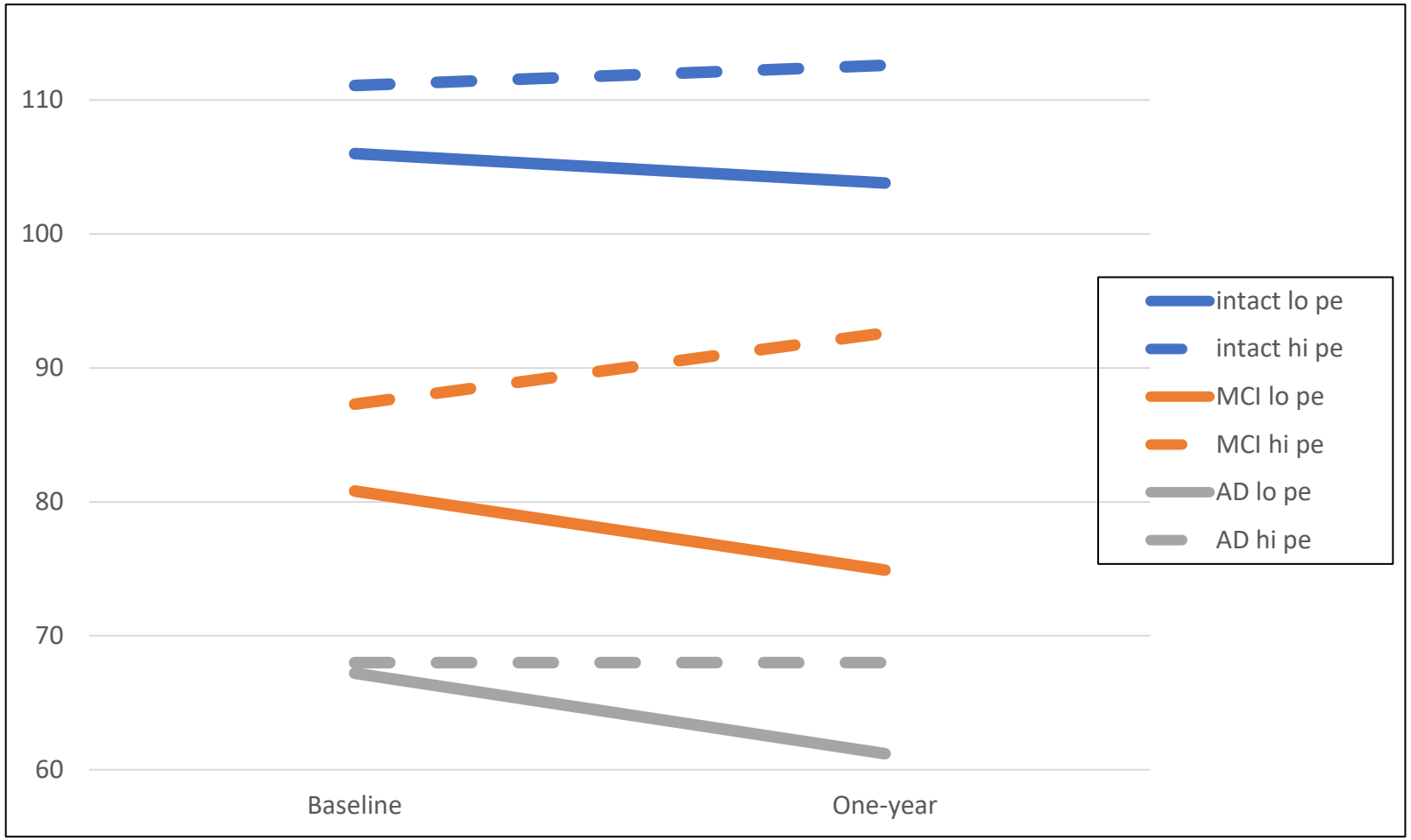
PE inform prognosis



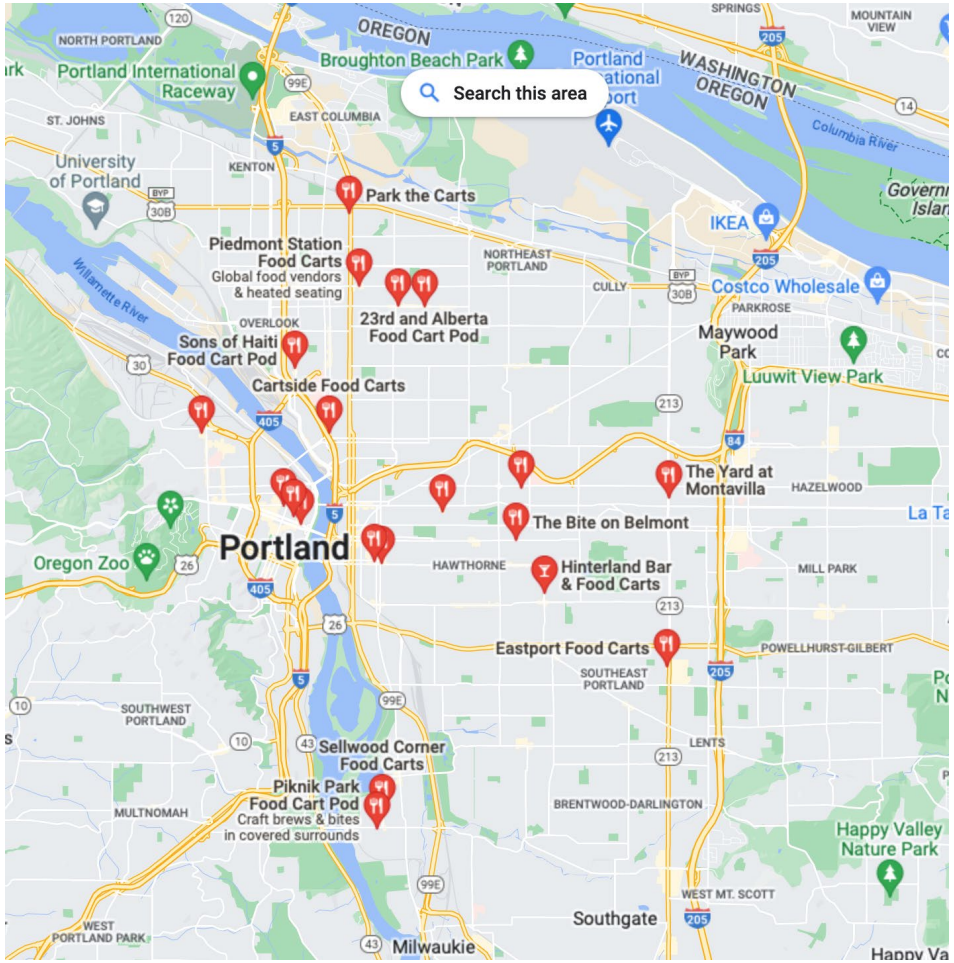
Long-term changes in cognition:

- Intact show stability/slight improvement
- MCI show slight decline
- AD show decline

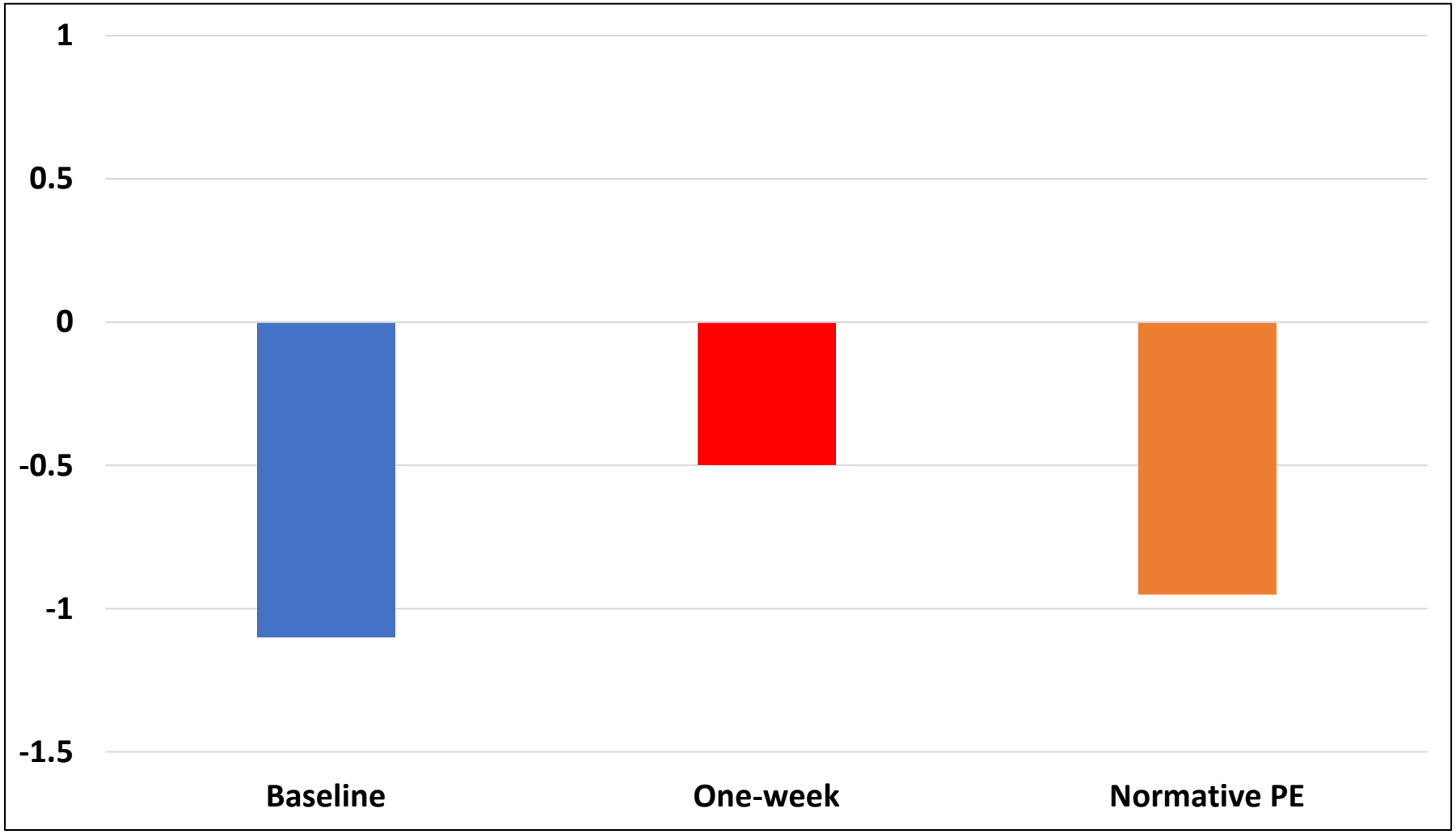
PE inform prognosis



PE across one week can tell us something about the individual's cognitive trajectory, which can inform prognosis


Search this area
Portland
Park the Carts
Piedmont Station Food Carts
Global food vendors & heated seating
23rd and Alberta Food Cart Pod
Sons of Haiti Food Cart Pod
Cartside Food Carts
The Yard at Montavilla
The Bite on Belmont
Hinterland Bar & Food Carts
Eastport Food Carts
Sellwood Corner Food Carts
Piknik Park Food Cart Pod
Craft brews & bites in covered surrounds
Portland International Raceway
Broughton Beach Park
University of Portland
IKEA
Costco Wholesale
Maywood Park
Luuwit View Park
Oregon Zoo
Happy Valley Nature Park
Southgate
Milwaukie
OREGON
WASHINGTON
Columbia River
Willamette River

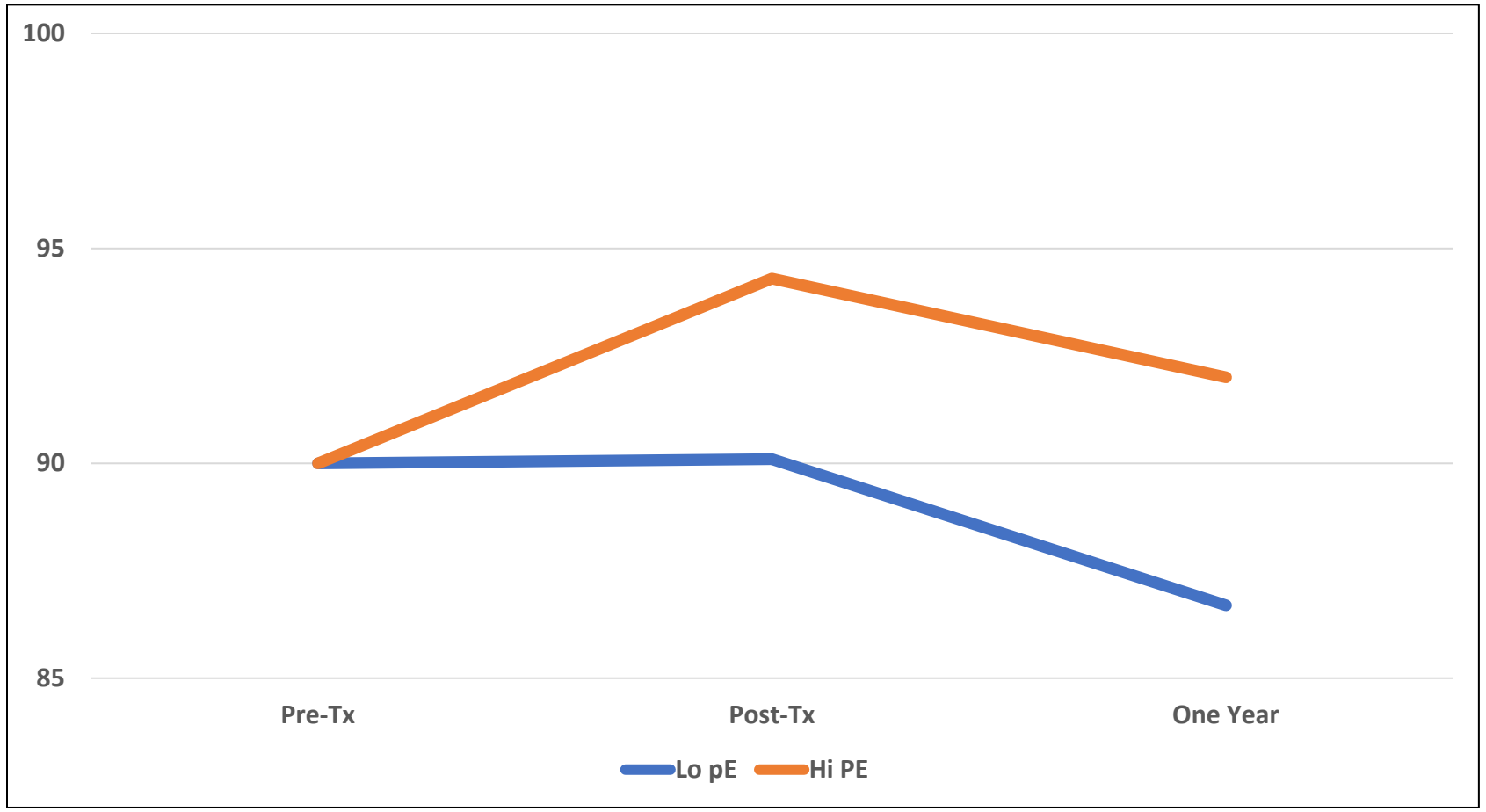
PE inform tx recommendations



MCI did show PE across one week, but it fell well below normative expectations

NIA R01: Duff (PI)
Pilot work funded by CoA

PE inform tx recommendations



After controlling for baseline differences:

- High PE group showed more benefit post-tx
- High PE group maintained more gain at one year

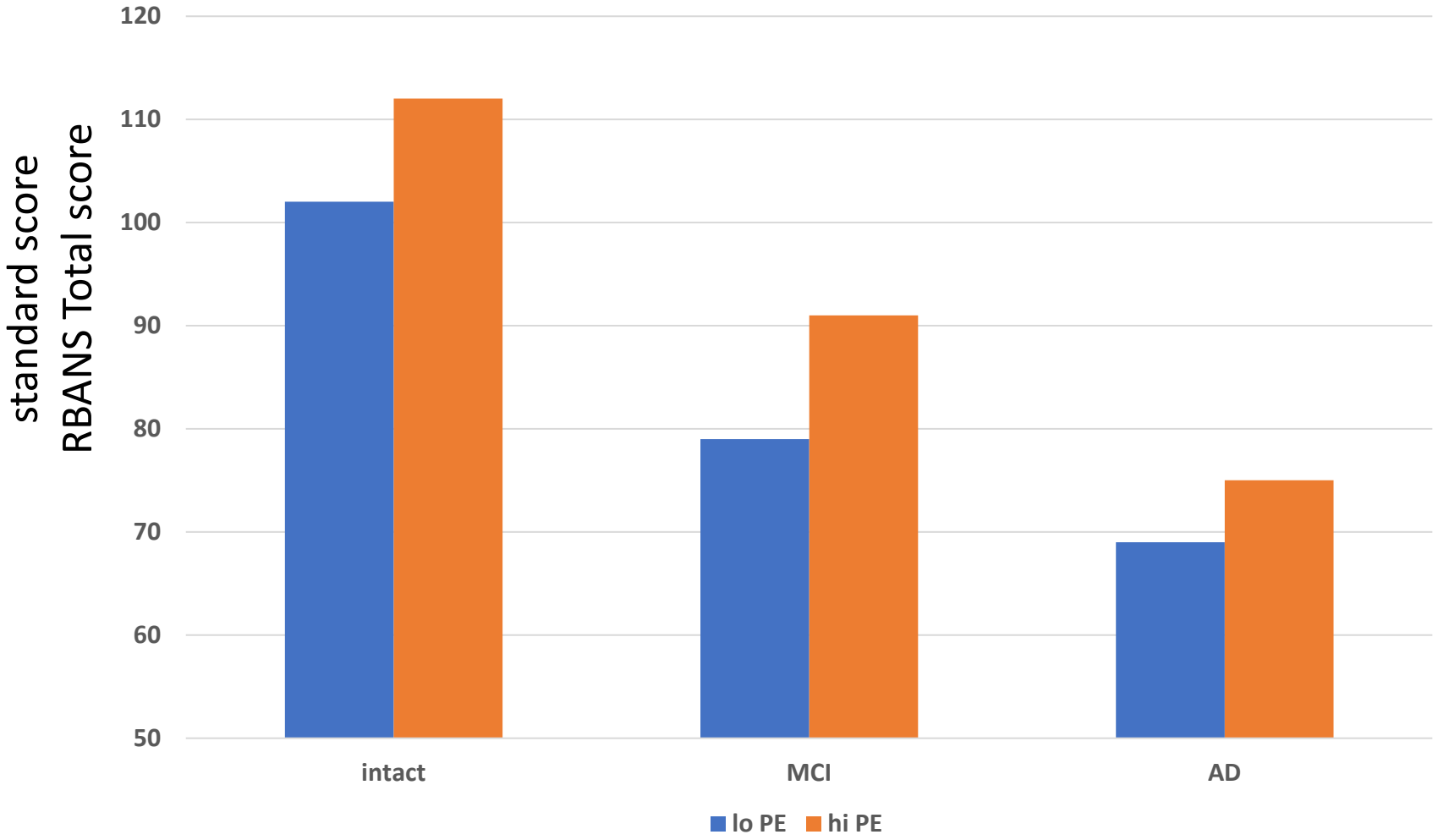
Duff et al., 2021


2023 Providence
Bridge Pedal


SPEED
50

PE informs cognitive resiliency

High and Low PE groups for each diagnostic group (intact, MCI, AD)



With-in each group:

- High PE group showed significantly higher global cognition
- PE seems to indicate cognitive reserve/resiliency

No within-group differences on age, education, sex, race, or ethnicity

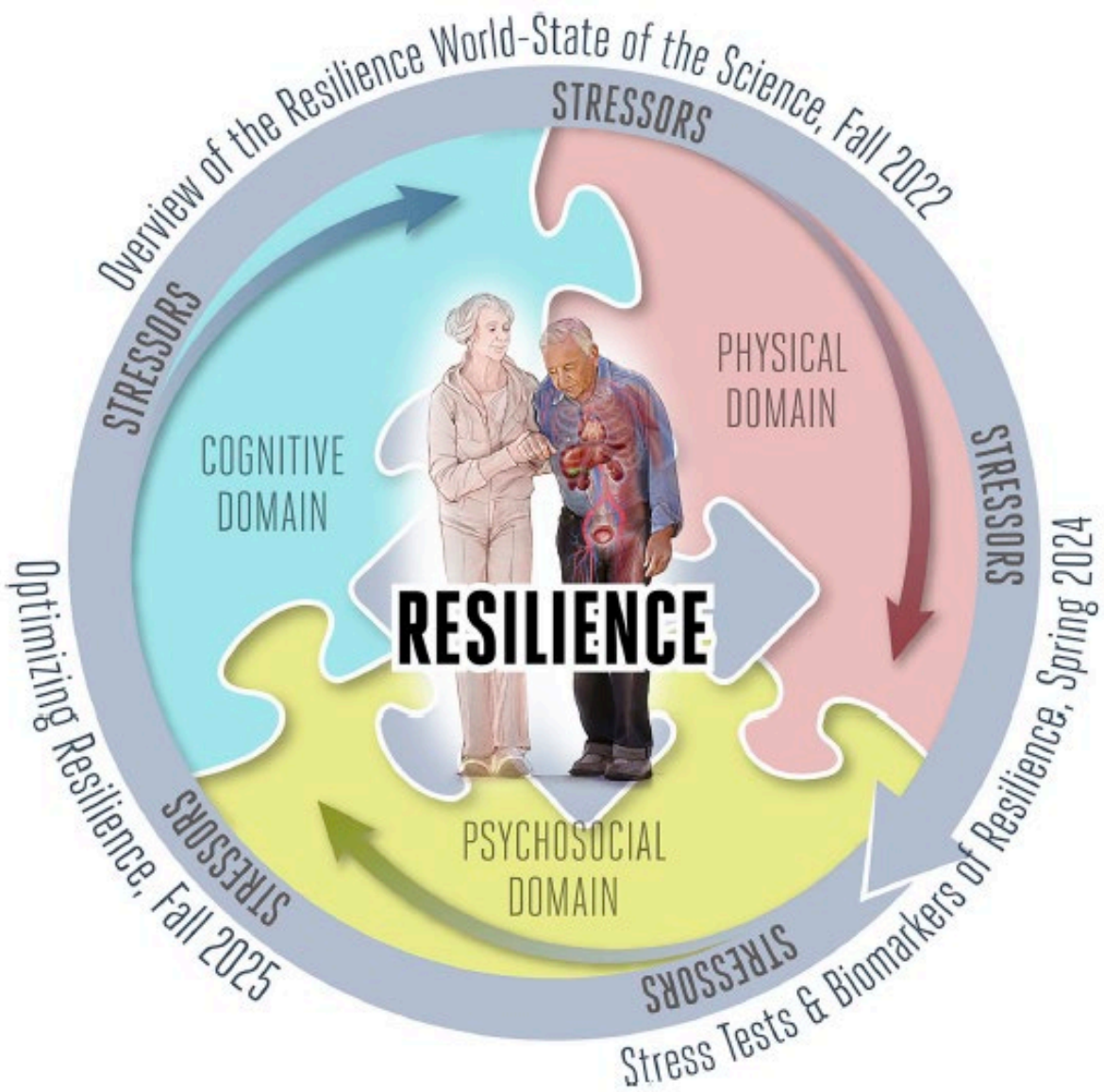
PE informs cognitive resiliency

- High and Low PE groups were all diagnosed with aMCI
  - No differences on age, education, sex, race, or ethnicity
  - High PE had significantly higher premorbid intellect
  - High PE had significantly higher RBANS Total at baseline, as well as higher scores on tests of learning and memory, attention, and processing speed
  - High PE had significantly higher scores on performance-based measures of daily activities at baseline
  - The informants of High PE rated them as more functionally intact at baseline
- In the face of the same cognitive disorder diagnosis, those with High PE appeared more cognitively resilient

Case Presentation

- 78 yo WWF
  - 14 yrs education, retired bookkeeper
  - Widowed x 5 yrs, lives alone, IADLs independent
  - HTN, T2DM, osteoarthritis, depression
  - Gradually worsening memory x 2 yrs
  - MoCA = 22/30 → 26/30
  - NP: imp memory → intact memory with large PE
  - What do PE tell us about her?

- Likely more intact than MCI (e.g., subjective cognitive decline, reverter)
- Less likely to worsen over the coming year, even if she is MCI
- More likely to respond to a cognitive intervention
- More likely to be cognitively resilient



Resilience within the Cognitive Domain

- PE may allow us to identify those with higher cognitive resilience and predict those who will have more favorable outcomes in response to cognitive insults

Abadir et al., 2023

	Annual rainfall	# days with rain per year
Salt Lake City	18 inches	91 days
Portland	36 inches	164 days

Summary

1. PE are a complex cognitive phenomenon that might inform us about cognitive reserve/plasticity/resiliency
2. Those with higher PE are more likely to be present with no/milder cognitive disorders, less likely to progress over time, more likely to respond to interventions, and more likely to be cognitively resilient
3. Being aware of and using this information in clinical cases can make for more personalized diagnoses, prognoses, and treatment recommendations for our patients

Thank You

Resilient Place for Healthy Aging

Rocky Mountain Geriatrics Conference, Utah

Andy Hong | City & Metropolitan Planning, University of Utah | Sep 27, 2023

AGENDA

1. Built Environments against Healthy Aging
2. Built Environments for Healthy Aging: Age-Friendly Communities
3. Aging in Place through the Pandemic
4. Resilience through Environmental Design

1

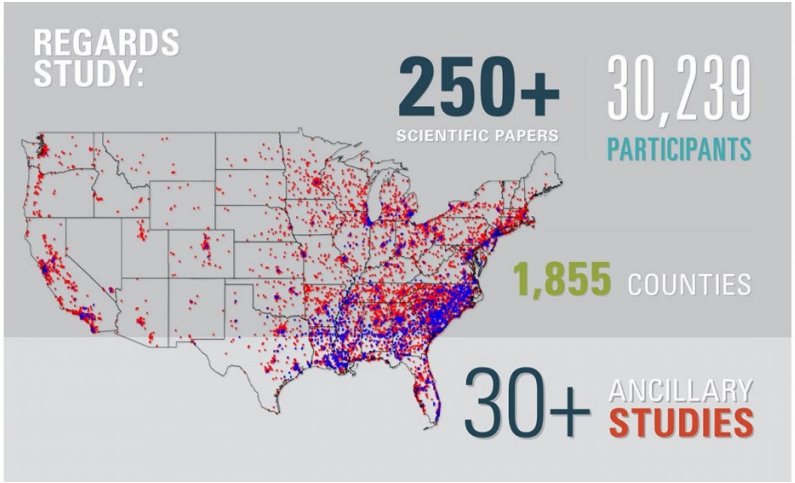
Built Environments against Healthy Aging

1st Case in Point: Sprawl Development


Homogenous Suburban Neighborhoods

Built Environment and Cognitive Health

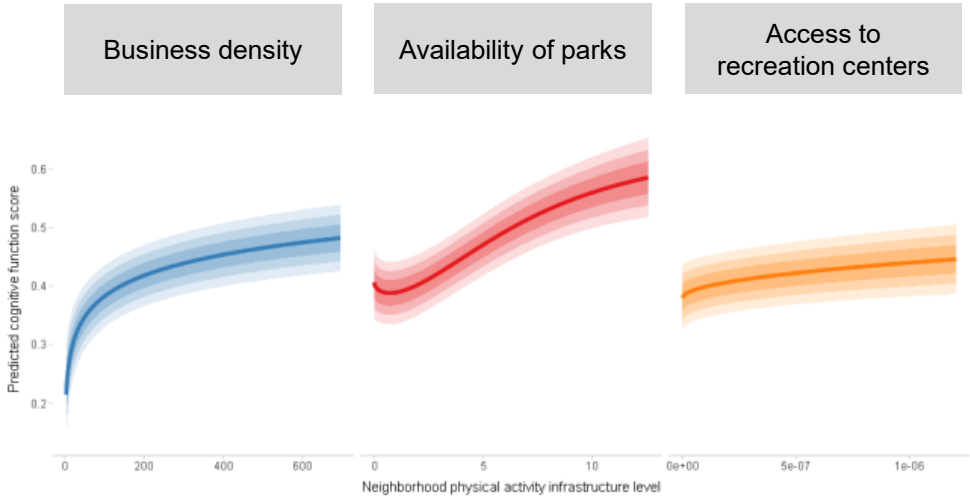
REGARDS: A national prospective cohort study



REGARDS
Add-on Study

Figure 2. Predicted cognitive function scores for individuals

Cognitive function score using five validated measures: verbal learning, memory, orientation, language, and executive function



Note: Shaded regions represent 50%, 75%, and 90% uncertainty intervals.

Finlay et al. (2021). *Preventive Medicine*, 150


Aging in Place,
Stuck without
Options:
No Transportation Options

The New York Times

OPINION

The City Looks Different When You're Older

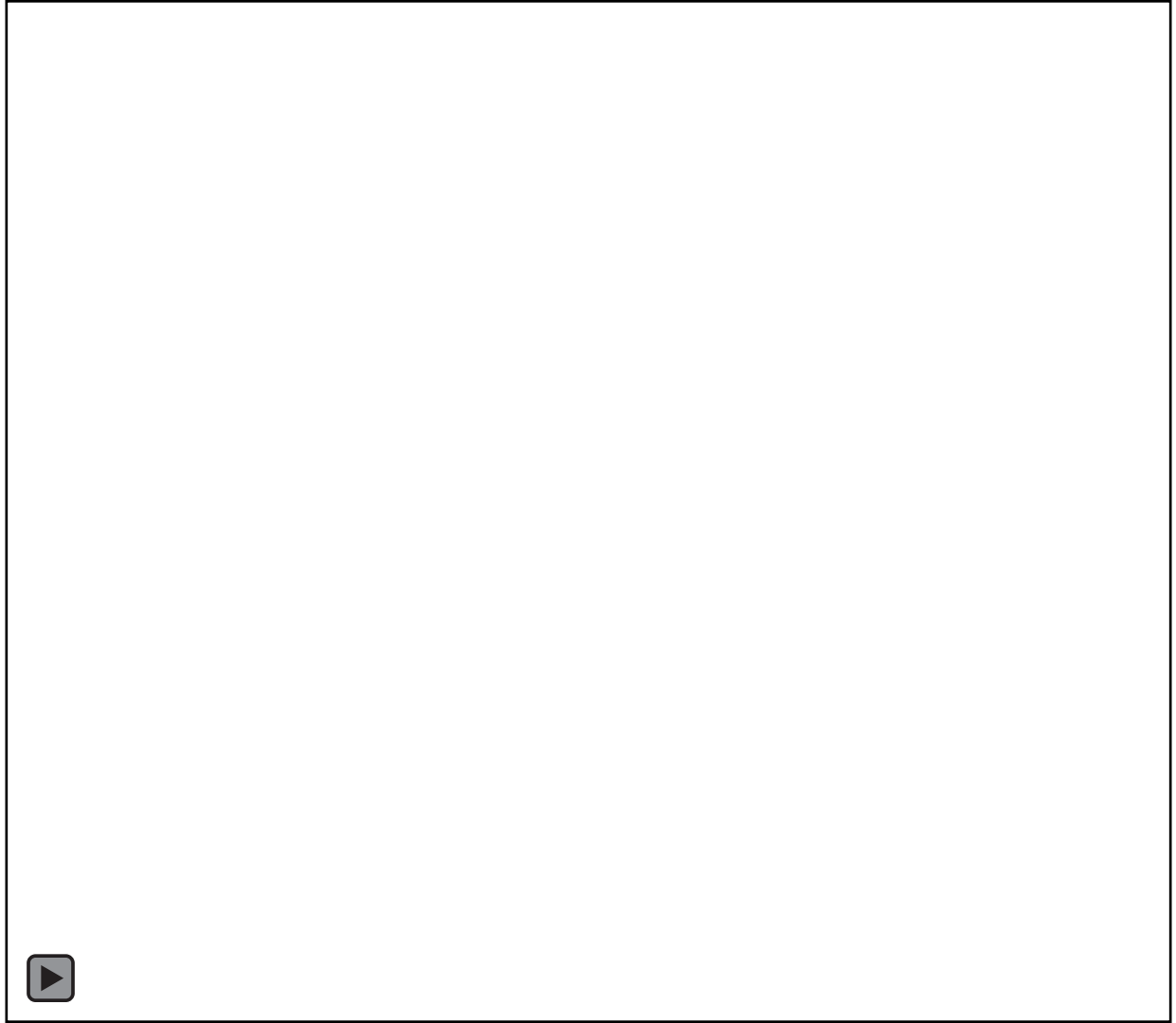
By Andy Hong

Dr. Hong is an assistant professor at the University of Utah and the director of its Healthy Aging and Resilient Places Lab.

Share full article 409

This article is part of "Can America Age Gracefully?," a series on how the country should prepare for the next big demographic shift.

Hong. (2023) New York Times
https://t.co/yQnK60FR7j



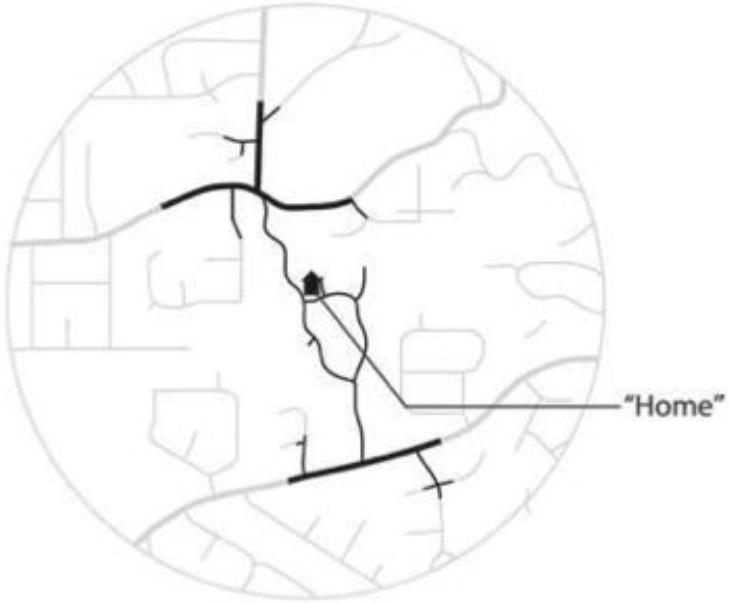
2nd Case in Point: Car-oriented Neighborhoods

Walkable Place

Car-oriented Place

Walkable Place

Car-oriented Place



— 10 minute walking range

• Major destinations


24 HOUR
FITNESS

Built Environment and Obesity

ORIGINAL ARTICLE
Obesity Biology and Integrated Physiology

Built environment influences on healthy eating and active living: The NEWPATH study

Lawrence D. Frank[1] | Alexander Bigazzi[2] | Andy Hong[3] | Leia Minaker[4] | Pat Fisher[5] | Kim D. Raine[6]

[1]Department of Urban Studies and Planning, University of California at San Diego, San Diego, California, USA
[2]Department of Civil Engineering, School of Community and Regional Planning, University of British Columbia, Vancouver, British Columbia, Canada
[3]Nuffield Department of Women's & Reproductive Health, University of Oxford, Hayes House, Oxford, UK
[4]School of Planning, Faculty of Environment, University of Waterloo, Waterloo, Ontario, Canada
[5]Region of Waterloo, Kitchener, Ontario, Canada
[6]School of Public Health, University of Alberta, Edmonton, Alberta, Canada

Correspondence
Lawrence D. Frank, Department of Urban Studies and Planning, University of California at San Diego, San Diego, CA, USA.
Email: ldfrank@ucsd.edu

Funding information
Grants were provided from the Heart and Stroke Foundation of Canada and the Region of Waterloo to support the study.

Abstract

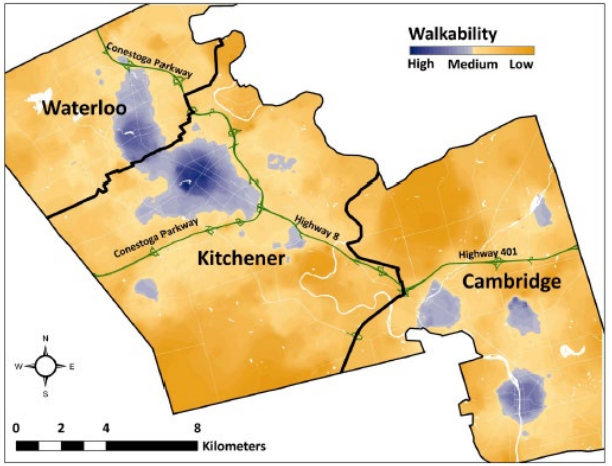
Objective: The Neighbourhood Environments in Waterloo: Patterns of Active Transportation and Health (NEWPATH) study examined built environment influences on travel, physical activity, food consumption, and health. This collaboration between researchers and practitioners in health and transportation planning is the first, to our knowledge, to integrate food purchasing, diet, travel, and objectively measured physical activity into a trip-destination protocol. This study simultaneously examines diet and physical activity relationships with BMI and waist circumference (WC).

Methods: Individual diet and travel diary data were linked to objective built-environment measures of walkability and retail food environments. BMI and WC were self-reported ($n = 1,160$). Some respondents wore accelerometers to objectively measure physical activity ($n = 549$). Pathways from the built environment through behavior (walking and eating) to BMI and WC were assessed using path analysis.

Results: Walkability was associated with lower BMI and WC through physical activity and active travel. Healthy retail food environments were associated with healthy eating and lower BMI and WC, whereas walkability and healthy retail food environments were insignificant ($p < 0.05$). Walkable neighborhoods had less healthy food environments, but active travel was not associated with healthy eating or caloric intake.

Conclusions: Findings highlight the importance of neighborhood walkability and food environments in shaping physical activity, diet, and obesity.

Region of Waterloo, Ontario, Canada



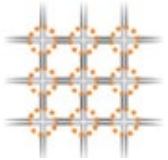
Walkability Index

Residential Density

Commercial Density

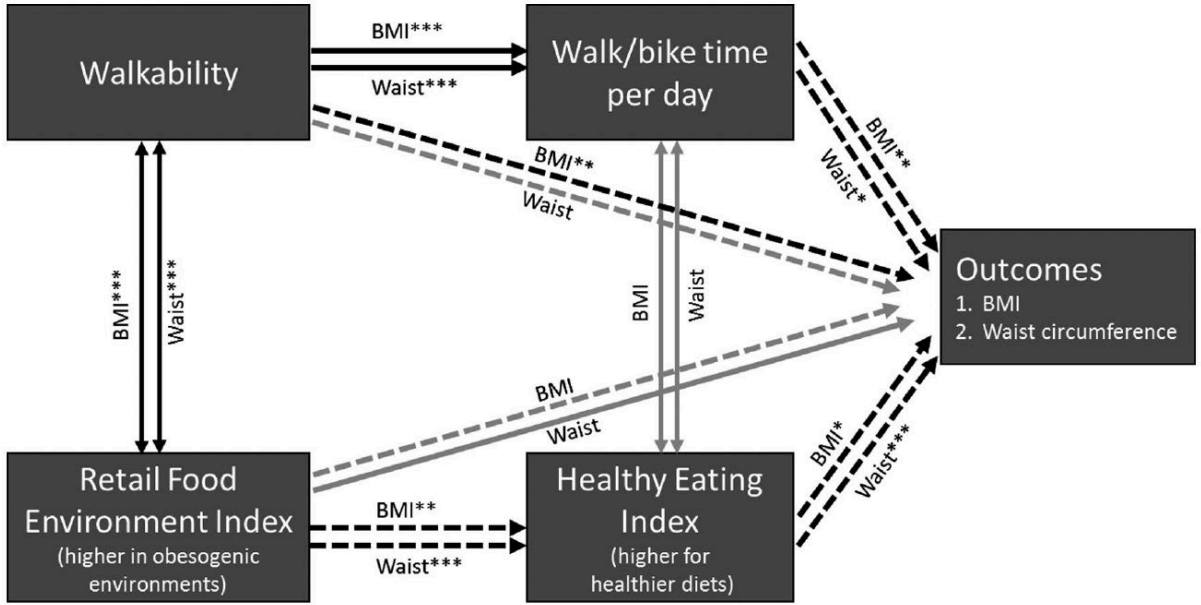
Land Use Mix

Intersection Density



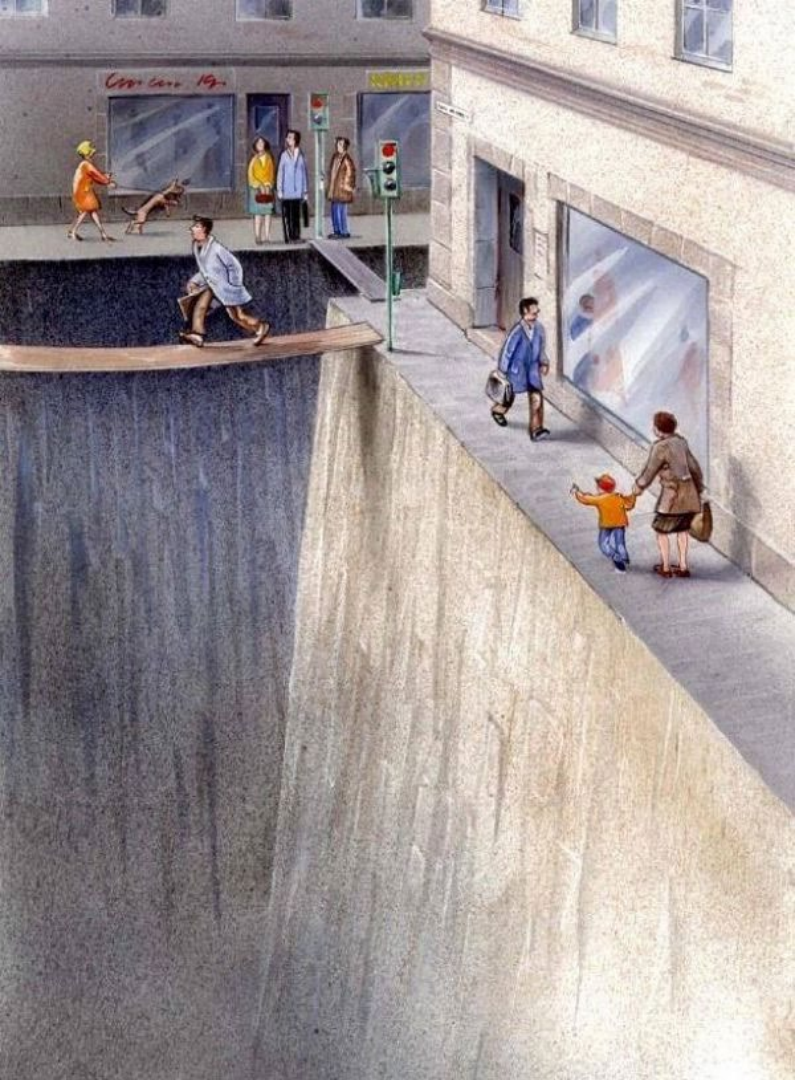
Frank et al. (2022). *Obesity*, 30: 424-434

Built Environment and Obesity



Frank et al. (2022). *Obesity*, 30: 424-434

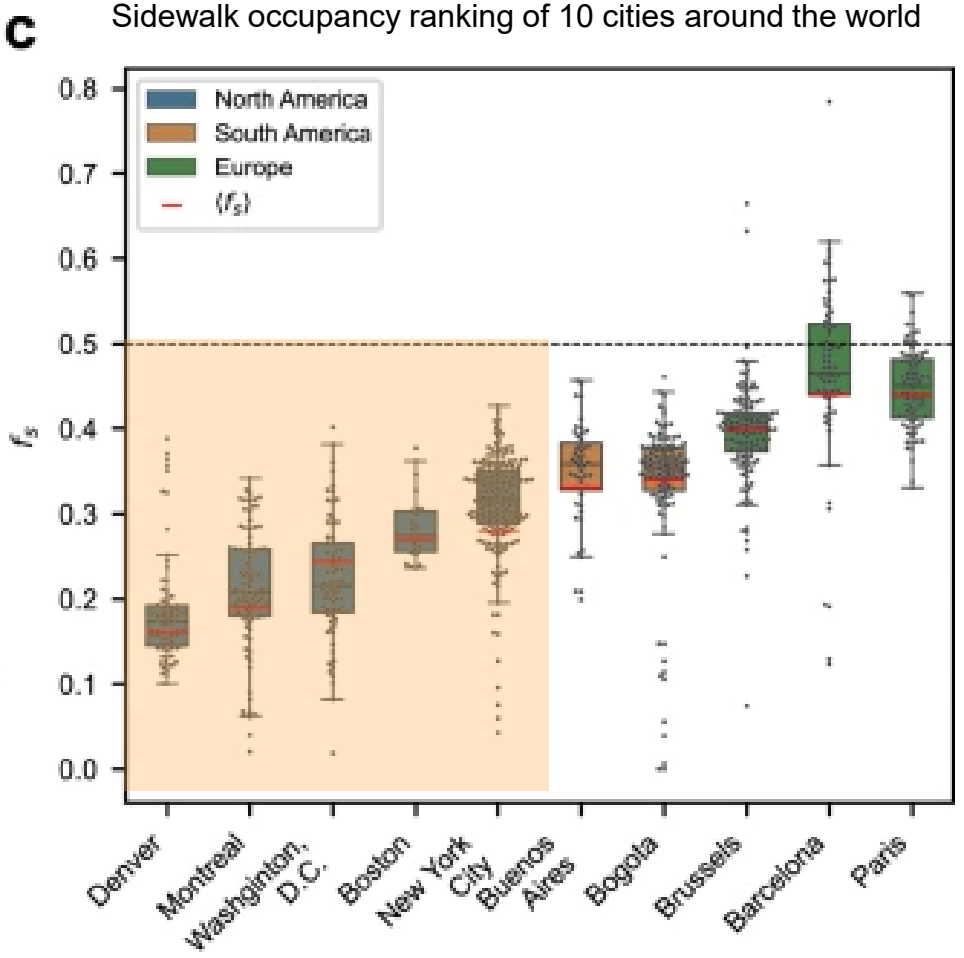
3rd Case in Point: No Place to Walk or Use Wheelchairs



Marginalization of pedestrians in the roadway space

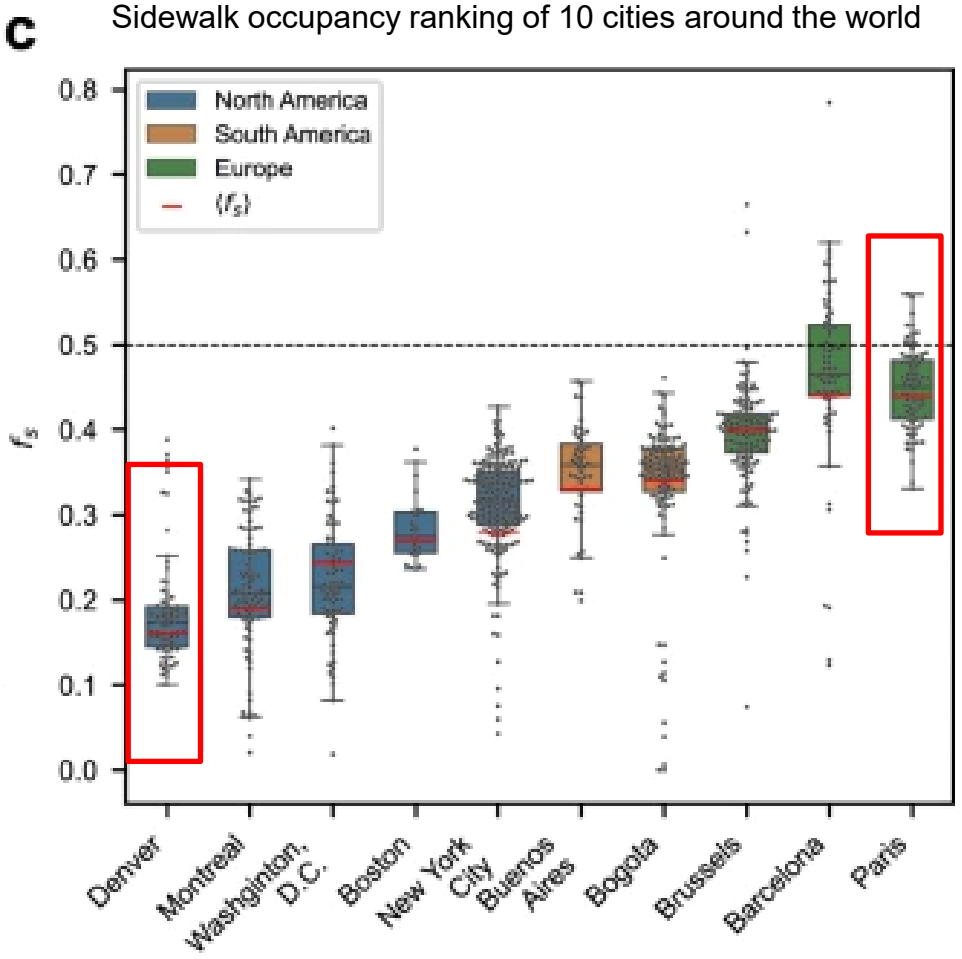
Karl Jilg/Swedish Road Administration

Sidewalk Occupancy: City Ranking



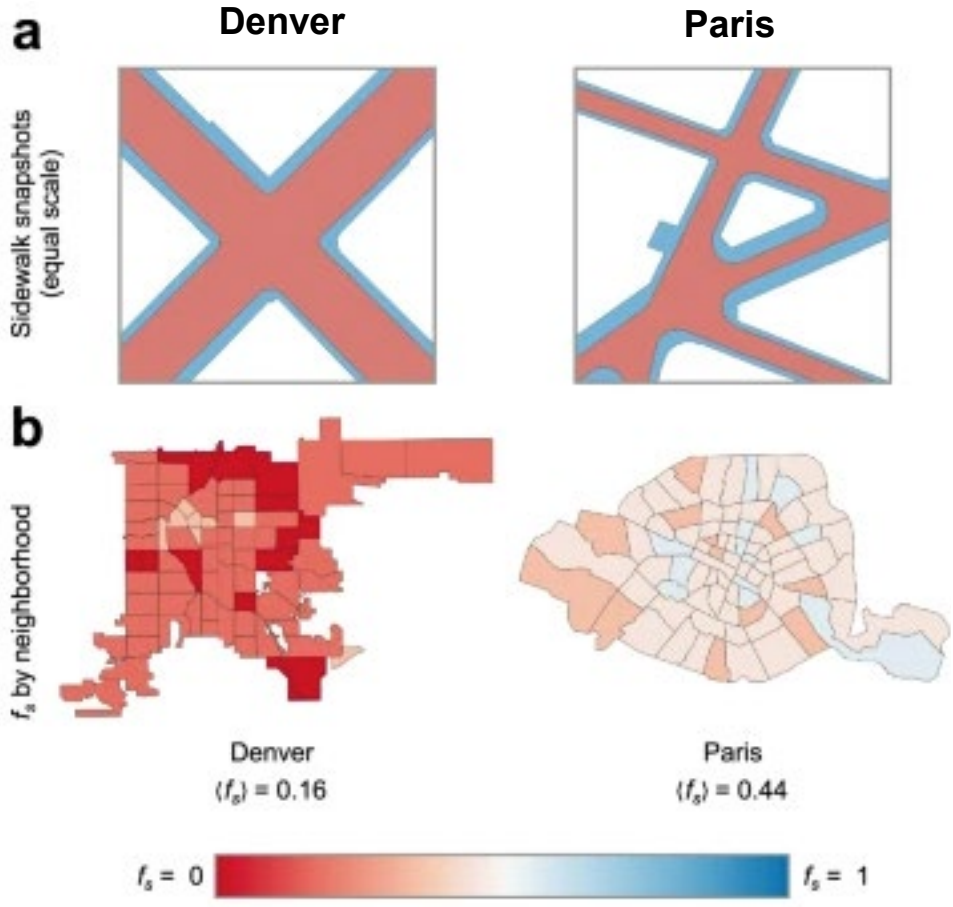
Rhoads et al. (2021). *Communications Physics*, 4(183)

Sidewalk Occupancy: City Ranking



Rhoads et al. (2021). *Communications Physics*, 4(183)

Sidewalk Occupancy: Denver vs Paris



Rhoads et al. (2021). *Communications Physics*, 4(183)

Our Next Infrastructure Crisis: Broken Sidewalks

And California moves to streamline approvals for transit, bike and pedestrian construction projects and more in this week's The Mobile City.

SANDY SMITH JUNE 17, 2020

SHARE

Smith (2020) *Next City*

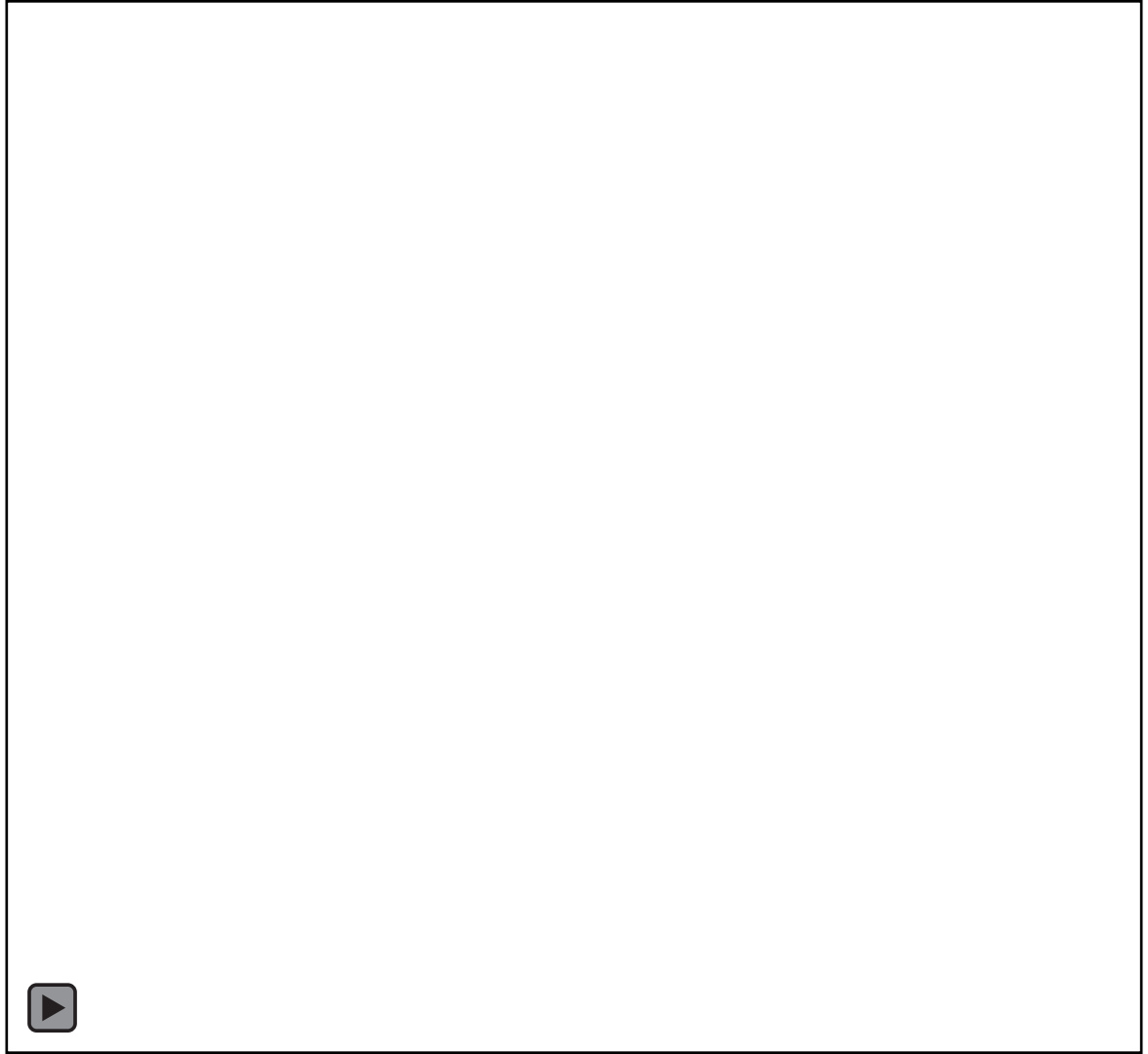
Bloomberg Subscribe

CityLab | Transportation

For Smaller Towns, Paying for Sidewalks Isn't Always Simple

Missoula considers a new approach to funding walkability as demand grows

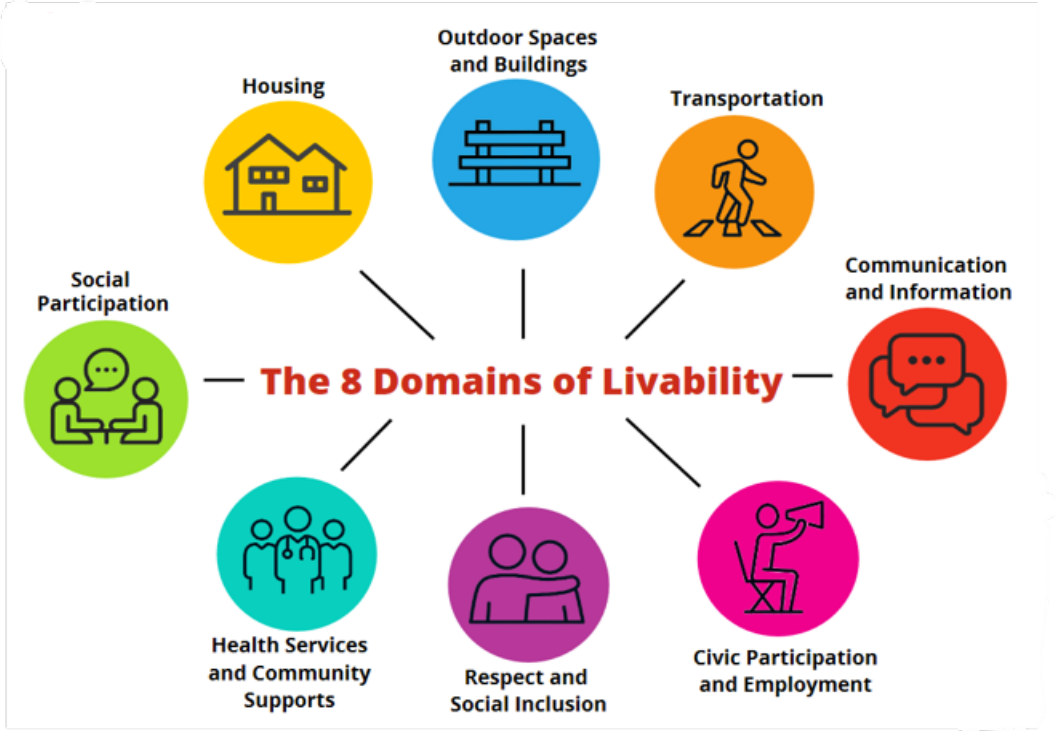
Berg. (2021). *Bloomberg*



2

Built Environment for Healthy Aging: Age-Friendly Communities

What is Age-Friendly Environment?



Age-Friendly Interventions for Health and Social Outcomes

International Journal of
Environmental Research and Public Health

MDPI

Review

Age-Friendly Community Interventions for Health and Social Outcomes: A Scoping Review

Andy Hong [1,2,*], Jessie Welch-Stockton [1,3], Ja Young Kim [1,2], Sarah L. Canham [1,2,3], Valerie Greer [1,4] and Michelle Sorweid [1,5,6]

[1] Healthy Aging and Resilient Places (HARP) Lab, College of Architecture + Planning, University of Utah, Salt Lake City, UT 84112, USA
[2] Department of City & Metropolitan Planning, College of Architecture + Planning, University of Utah, Salt Lake City, UT 84112, USA
[3] College of Social Work, University of Utah, Salt Lake City, UT 84112, USA
[4] School of Architecture, College of Architecture + Planning, University of Utah, Salt Lake City, UT 84112, USA
[5] Aging Brain Care Program, University of Utah Health, Salt Lake City, UT 84132, USA
[6] Division of Geriatrics, Department of Internal Medicine, University of Utah Health, Salt Lake City, UT 84132, USA
* Correspondence: a.hong@utah.edu; Tel.: +1-(801)-585-7102

Abstract: To address the numerous challenges associated with aging, increased attention has been given to the development of age-friendly cities and communities (AFCC) to promote healthy aging and social participation. However, limited evidence exists for addressing both health and social needs through the AFCC framework. We address this gap by conducting a scoping review of the interventions that target both health and social outcomes within the purview of the AFCC framework. The results showed that many of the successful interventions used a partnership model and behavioral change theories to inform the program design and implementation. The results also indicated that social participation and engagement played a key role in making the interventions successful. However, the results revealed that the literature is dominated by person-focused approaches. Future research should focus more on evaluating environmental-focused interventions and develop a holistic framework that combines both person- and environment-based approaches to healthy aging.

Keywords: age-friendly cities and communities; age-friendly intervention; health outcomes; social outcomes

Citation: Hong, A.; Welch-Stockton, J.; Kim, J.Y.; Canham, S.L.; Greer, V.; Sorweid, M. Age-Friendly Community Interventions for Health and Social Outcomes: A Scoping Review. *Int. J. Environ. Res. Public Health* **2023**, *20*, 2554. https://

Age-Friendly Interventions around the World

Figure A1. Interactive story map showing some of the key age-friendly community interventions around the world (https://www.harp.utah.edu/storymaps) (accessed on 2 January 2023).

Hong et al. (2022). *IJERPH*, 20(30): 2554

Age-Friendly Interventions for Health and Social Outcomes

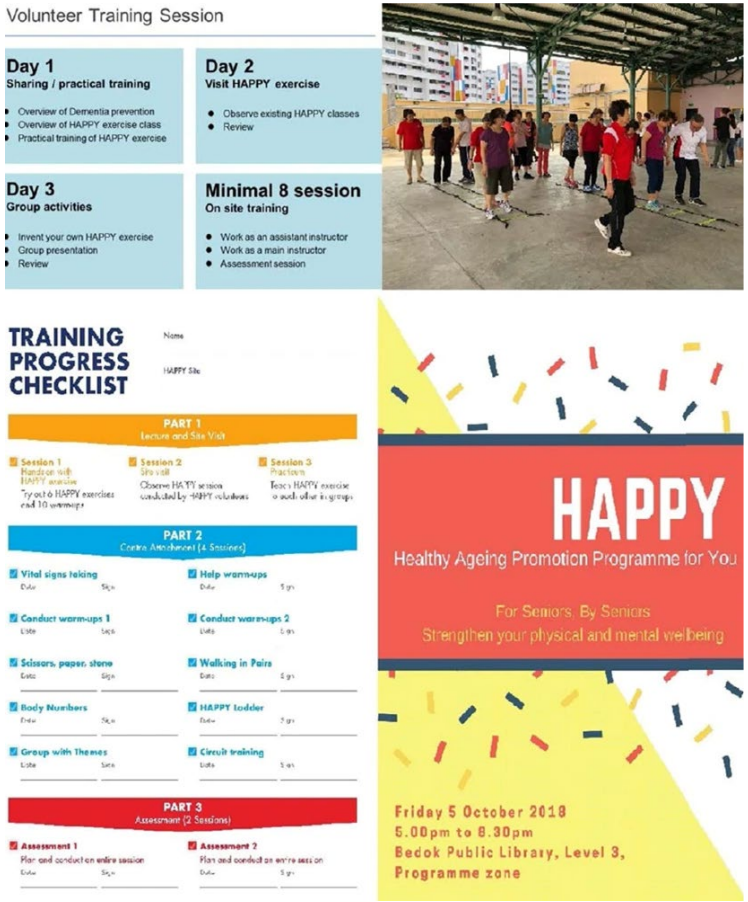
- Resistance training program
- Fall-prevention program
- Tai Chi program
- Exercise program
- Healthy ageing program

- Cognitive stimulation / training
- University program
- Peer-led education
- Comedy improvisation program
- Family-based empowerment program
- Health promotion program

- Senior living enhancement program
- NORC supportive service
- Health education and exercise
- Multi-center health promotion

- Free bus pass
- Online social network and technology training

Hong et al. (2022). *IJERPH*, 20(30): 2554



'HAPPY' Program from Singapore

Physical activity interventions

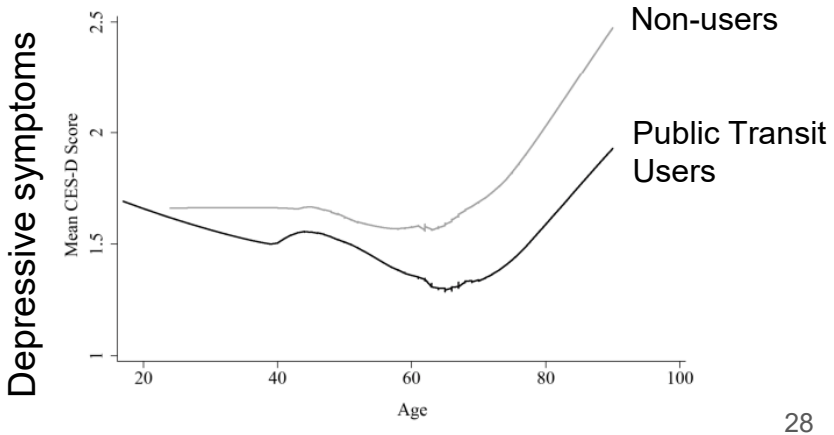
- **Objectives**:
  - Observe improvements to cognition
  - Observe overall health and social outcomes
- **Population**: Older adults 60+
- **Intervention**: 3-month community-based exercise program
- **Results**: Significant improvements in cognitive, social, and physical functions

Merchant et al (2021) *J Nutr Health Aging*

Other interventions

Free Bus Pass Program from England

- **Objectives**: Analyze the impact of free bus passes on the mental health of older people in England
- **Population**: Older adults in England
- **Intervention**: Free bus passes for qualifying older adults
- **Results**: Overall decreases in depressive symptoms and feelings of loneliness



Reinhart et al (2018) *J Epidemiol Community Health*

3

Aging in Place through the Pandemic

Photovoice Study of Older Adults during COVID-19

Ageing & Society (2023), 1–24
doi:10.1017/S0144686X23000211

ARTICLE

Shifting perspectives: outlooks on ageing in place in the COVID-19 era

Valerie Greer[1], Sarah L. Canham[1,2], Andy Hong[1,3], Natalie Caylor[4] and Jessica Van Natter[2]

[1]College of Architecture and Planning, University of Utah, Salt Lake City, UT, USA, [2]College of Social Work at the University of Utah, Salt Lake City, UT, USA, [3]Healthy Aging and Resilient Places Lab, College of Architecture and Planning, University of Utah, Salt Lake City, UT, USA and [4]Medical College of Georgia, University of Utah, Salt Lake City, UT, USA
Corresponding author: Valerie Greer; Email: valerie.greer@utah.edu

(Accepted 6 March 2023)

Abstract
Given the significant impact the pandemic has had on the lives of older adults, research is needed to understand how conceptions of ageing in place and attitudes about living independently may have shifted during a time marked by significant environmental change. There is a gap in knowledge about how older adults characterise positive support for ageing in place in response to rapid changes in physical and social environments, including home confinement, reduced social interaction and greater barriers to resources. To fill this knowledge gap, we conducted a photovoice study with community-dwelling older adults (N = 17)

Participant 6: This is on the street that I live on. And it just is, this is my very own neighborhood and this is looking east. And I took this picture because there are a lot of single women on my street. And we kind of help each other out, were sort of varying ages. And that just reminded me how important that is to have a little cohort of little old ladies. There's one little old man, he's 98. We'd like to adopt him too.

Interviewer: And how does this support or not support your idea of aging in place?

Participant 6: I think it helps, you know. I mean, having some people you know, you have to ... Yeah, and people you know are going to help you. Wherever you are is important. So, I think it supports having a nice little neighborhood to be in.

Interviewer: And then how has the pandemic changed how you value this?

Participant 6: I think that it helped even more because I think we all got to know each other a little bit more because we've talked from across the street, it's not a street you...I mean you can stand in the middle of the street for a while there before anybody comes, but we would, you know, holler across when we saw each other and stuff like that, and I think that's been really, that increased the closeness of us.

Participant 7: That's my workout, front room. And that just represented my online class that I took last summer through the senior center that I belong to they had; they (had a program) giving credit for teaching seniors, um, routines and exercises. So I got to do that on zoom last summer.

Interviewer: What does that mean to you?

Participant 7: Um, it was; it was actually not bad for all, all of us. I had two trainers because there weren't enough older people to do it. So I had two young women that were teaching me, they'd take turns, and it worked out really good because they didn't have to leave their apartment. I didn't have to leave the house. We, we had lots of fun doing exercises and talking, and it was, it was actually quite fun.

Interviewer: That's cool. What about this photo supports or doesn't support your ability to age in place?

Participant 7: Well, of course, exercise is always good for everyone, but especially at your age, because your body goes down the tube faster, if you, and so I really try to exercise every day, just a little bit. And just to keep my muscles as strong as I can.

Interviewer: How has the pandemic changed the way you view your value what you captured here?

Participant 7: Well, it really made me value the computer, and the internet and the technology really gave me another way to keep in touch with the world. That's cool.

Greer et al (2023). *Ageing & Society.*

Photovoice Study of Older Adults during COVID-19

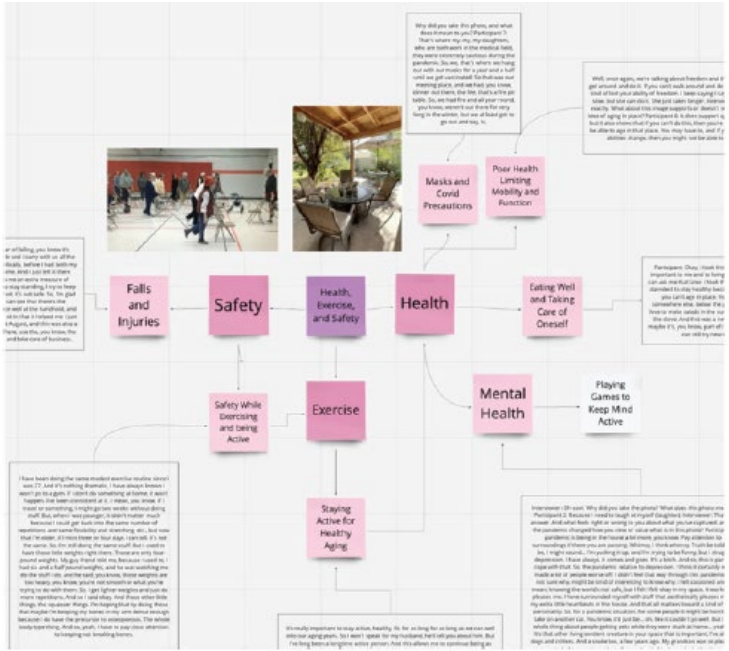


Figure 2. Example of initial mapping of categories on Miro board.

Table 3. Coding and thematic analysis

Theme	Key points
1. 'Staying close to people who are close to you'	Ability to maintain in-person contact with 'close others', *i.e.* friends and family; physical proximity or a sense of closeness is defined via micro-, meso- and macro-scales; adaptations noted to spaces and/or routines that enable gathering
2. Balancing social connectivity with safety	Experiences of interconnectivity are described with positive and negative associations; a common aspect to positivity is new-found/improved relationships with friends and neighbours; a negative aspect to connectivity is being in unmasked/crowded places where people appear to disregard health and safety
3. 'To get outside and just breathe fresh air'	Outdoors is revalued as an outlet for maintaining physical and mental health; open spaces are 'go to' destinations because physical distancing is easily maintained; diversity in types of open spaces range from urban to rural; descriptions of physical exercise activities range in intensity
4. Openness to new ideas	Creative and intellectual pursuits are linked to learning, growing and pursuing goals; activities in this category include hobbies and crafts, reading, cooking, gardening, music and arts; discovery and engagement with meaningful activities are cited as sources of renewal and positivity during the pandemic
5. Nurturing perspective through inner beliefs	Inner belief systems, values and personal outlooks on life are a framework for making sense of change and disruption; keeping hardship in perspective; source of connection to inner beliefs is often place-based, and ranges from physical settings, *e.g.* church/temple, to outdoor or natural phenomena, *e.g.* clouds

Greer et al (2023). *Ageing & Society.*

From Sheltered in Place to Thriving in Place

The Gerontologist, 2023, XX, 1–11
https://doi.org/10.1093/geront/gnad087
Advance access publication 7 July 2023
Research Article

THE GERONTOLOGICAL SOCIETY OF AMERICA

OXFORD

From Sheltered in Place to Thriving in Place: Pandemic Places of Aging

Valerie Chang Greer, AIA, MArch,[1,*] Andy Hong, PhD,[1,2] Sarah L. Canham, PhD,[1,3] James Agutter, MArch,[1] Ivis Garcia, PhD,[4] Jess M. Van Natter, BA,[2] and Natalie Caylor, BA[5]

[1]College of Architecture and Planning, University of Utah, Salt Lake City, Utah, USA.
[2]Healthy Aging and Resilient Places Lab, College of Architecture and Planning, University of Utah, Salt Lake City, Utah, USA.
[3]College of Social Work, University of Utah, Salt Lake City, Utah, USA.
[4]Department of Architecture and Urban Planning, Texas A&M University, College Station, Texas, USA.
[5]Medical College of Georgia, Augusta, Georgia, USA.

*Address correspondence to: Valerie Chang Greer, AIA, MArch. E-mail: valerie.greer@utah.edu

Decision Editor: Andrea Gilmore-Bykovskyi, PhD, RN

Abstract

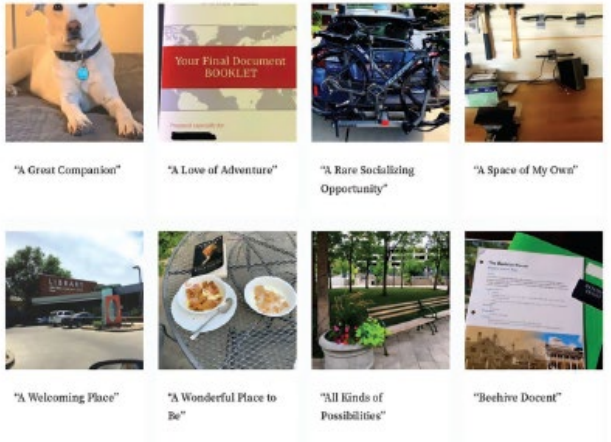
Background and Objectives: Response to the coronavirus disease 2019 pandemic required rapid changes to physical, social, and technological environments. There is a need to understand how independent-living older adults are adapting to pandemic-borne transformations of place and how environmental factors may shape experiences of aging well in the context of a public health emergency response.

Research Design and Methods: We conducted a photovoice study to examine the characteristics associated with aging in place. Our study investigated how independent-living older adults characterized aging in a "right" place approximately 1 year after the onset of the pandemic.

Results: Six themes categorized into 2 groups capture how older adults describe a "right" place to age. The first category, "places as enactors of identity and belonging," describes the significance of places contributing to intimate relationships, social connections, and a sense of personal continuity. The second category, "places as facilitators of activities and values," recognizes environments that promote health, hobbies, goals, and belief systems. Participants reported modifying their daily living environments with increased use of technology and more time outdoors.

Discussion and Implications: Our findings emphasize older adults' active engagement with place and strategies used to maintain healthy aging despite public health restrictions. The results also identify place-based characteristics that may help overcome stressful circumstances from older adults' perspectives. These findings inform pathways to pursue to facilitate resiliency for aging in place.

Keywords: Aging in place, Covid-19, Older people, Photovoice



Person-place dynamics that characterize aging in a 'right' place during the pandemic

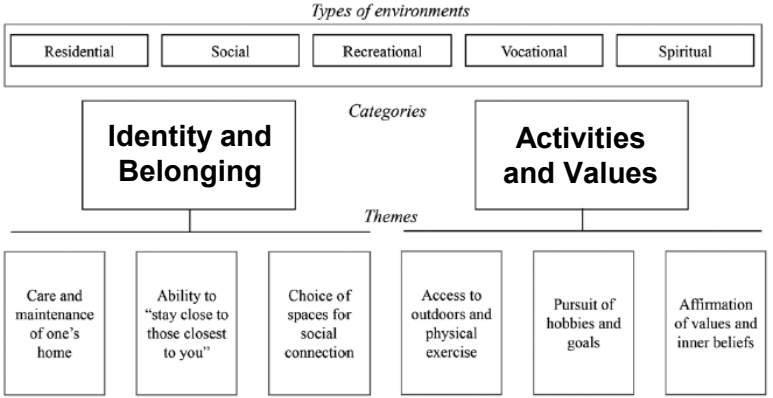
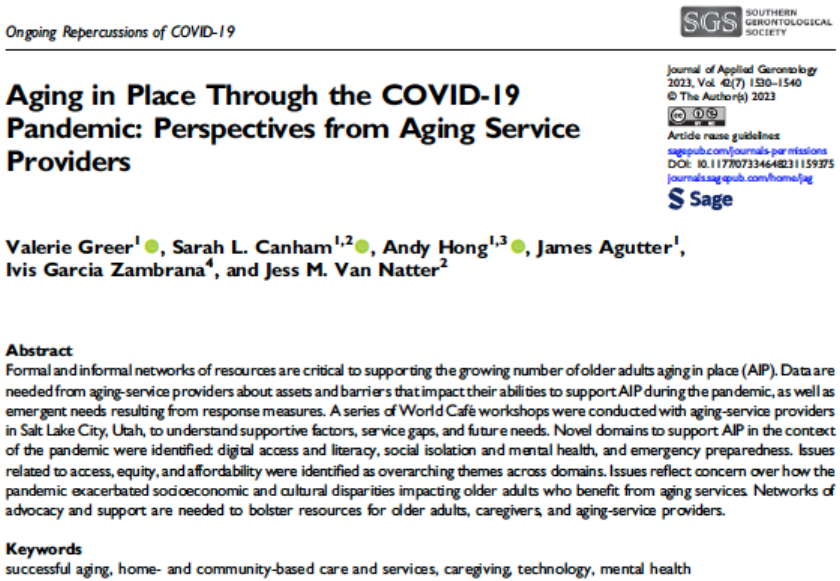


Figure 3. Characteristics of aging in a "right" place during the pandemic.

Greer et al (2023). *Gerontologist.*

Aging in Place: Perspectives from Aging Service Providers



Ongoing Repercussions of COVID-19

SGS SOUTHERN GERONTOLOGICAL SOCIETY

Aging in Place Through the COVID-19 Pandemic: Perspectives from Aging Service Providers

Journal of Applied Gerontology
2023, Vol. 42(7) 1530–1540

DOI: 10.1177/07334648231159375
journals.sagepub.com/home/jag
Sage

Valerie Greer[1], Sarah L. Canham[1,2], Andy Hong[1,3], James Agutter[1], Ivis Garcia Zambrana[4], and Jess M. Van Natter[2]

Abstract
Formal and informal networks of resources are critical to supporting the growing number of older adults aging in place (AIP). Data are needed from aging-service providers about assets and barriers that impact their abilities to support AIP during the pandemic, as well as emergent needs resulting from response measures. A series of World Café workshops were conducted with aging-service providers in Salt Lake City, Utah, to understand supportive factors, service gaps, and future needs. Novel domains to support AIP in the context of the pandemic were identified: digital access and literacy, social isolation and mental health, and emergency preparedness. Issues related to access, equity, and affordability were identified as overarching themes across domains. Issues reflect concern over how the pandemic exacerbated socioeconomic and cultural disparities impacting older adults who benefit from aging services. Networks of advocacy and support are needed to bolster resources for older adults, caregivers, and aging-service providers.

Keywords
successful aging, home- and community-based care and services, caregiving, technology, mental health

Technology Access and Digital Literacy

> *Technology is a two-edged sword; for many people, (it) expanded options […], but the individuals who don't have technology...that is obviously a bigger issue*

Social Isolation and Mental Health

> *Seniors who were receiving services in offices for mental health support were cut off … [they] are low-income, struggle with technology and isolation …*

Emergency Preparedness and Home Safety

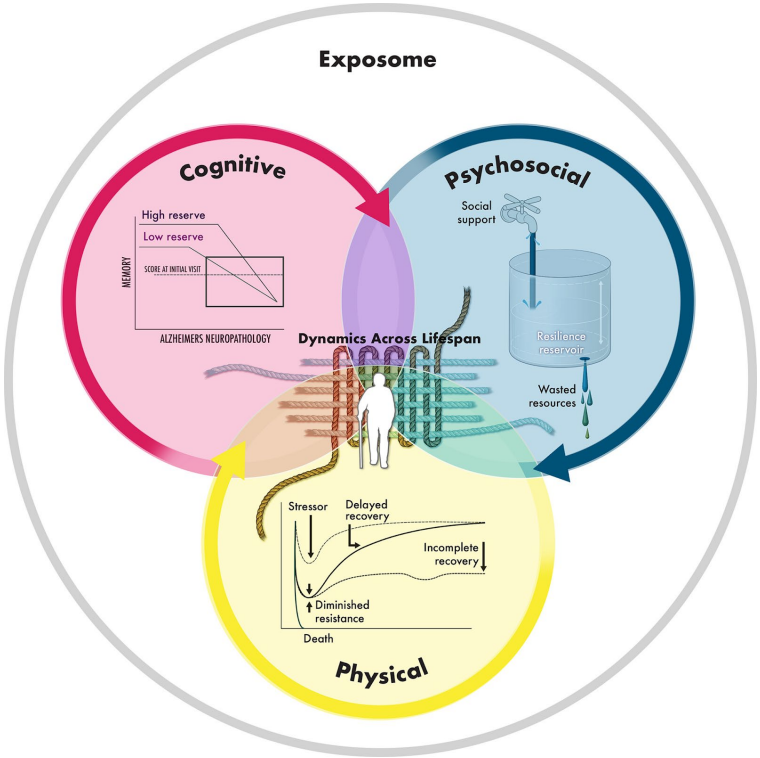
> *So many people didn't have situations in place where they could be home and be safe without being connected to resources ...*

Greer et al (2023). *J. Applied Gerontology*

4

Resilience through Environmental Design

Domains of Resilience in Aging

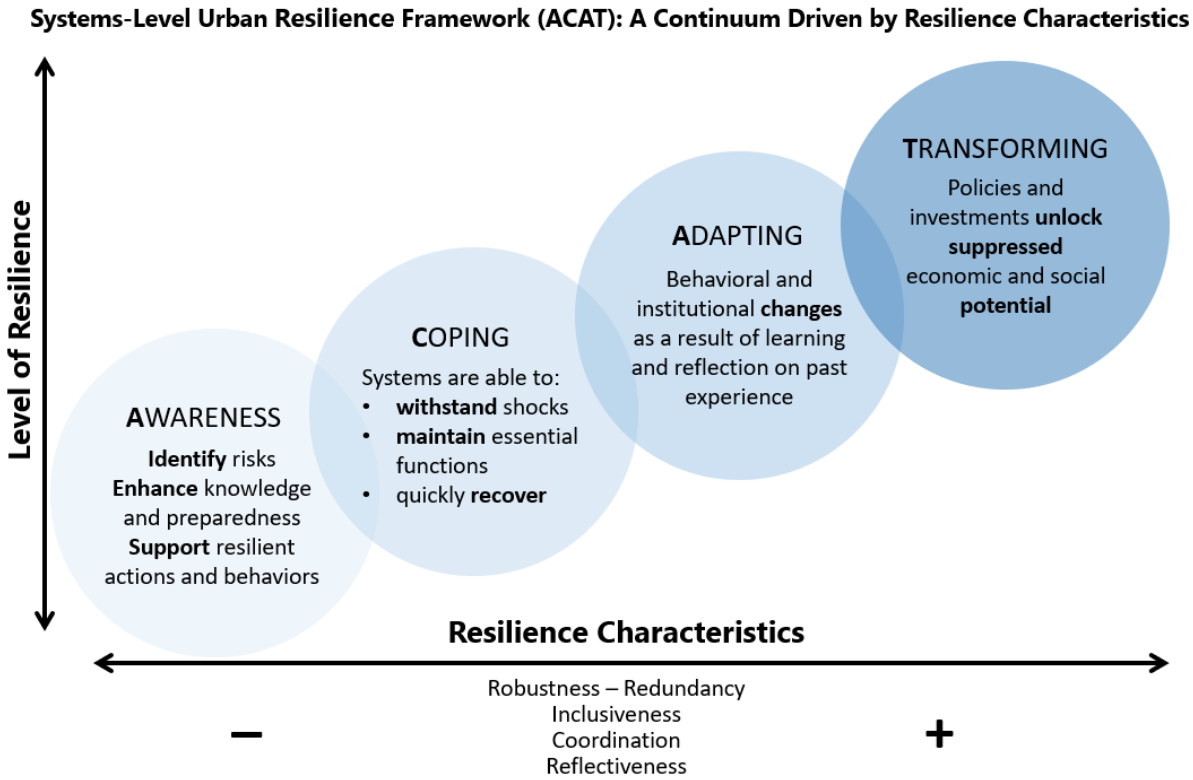


Resilience

> Ability to bounce back from adversity

Abadir et al. (2023). *J Am Geriatr Soc*.

Urban Resilience Framework



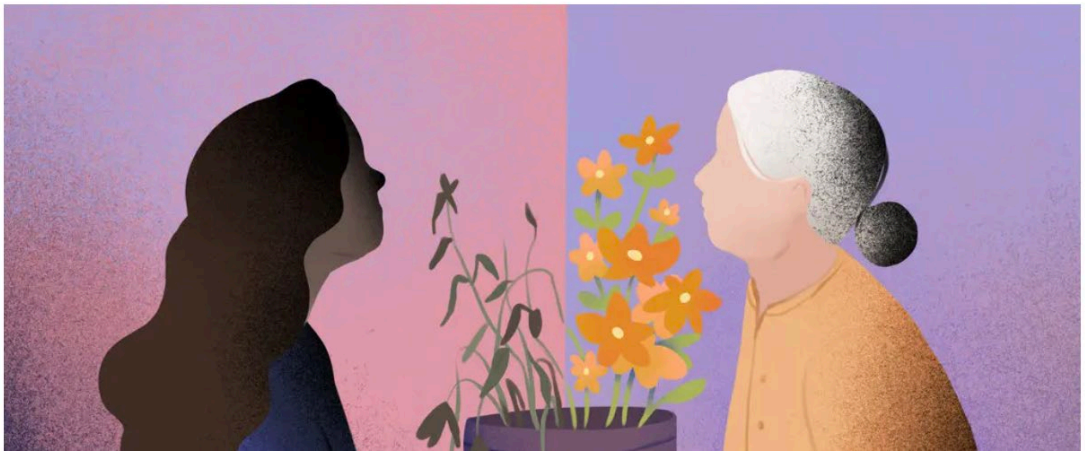
World Bank (2019) Building Urban Resilience.
https://ieg.worldbankgroup.org/evaluations/urban-resilience

The New York Times

MIND

Why Older People Managed to Stay Happier Through the Pandemic

New surveys over the last year show that the ability to cope improves with age.



Carey (2021). *New York Times*

Resilient Place

> A place that enables individuals to identify and withstand challenges while helping them to adapt and transform their environment

Four Approaches to Resilient Place

> A place that enables individuals to identify and withstand challenges while helping them to adapt and transform their environment

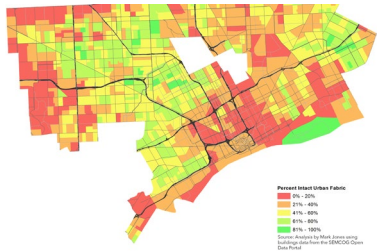
1. Increasing awareness
2. Developing coping mechanims
3. Providing adapting strategies
4. Enabling transformation

1. Resilient Place through Increasing Awareness

Macro/Meso Level

Community / neighborhood scale

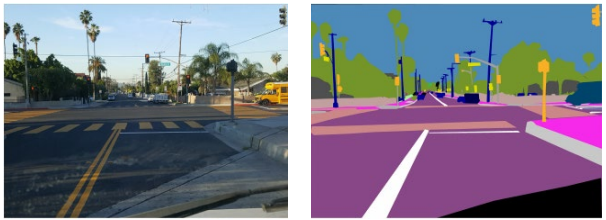
Spatial Mapping Techniques



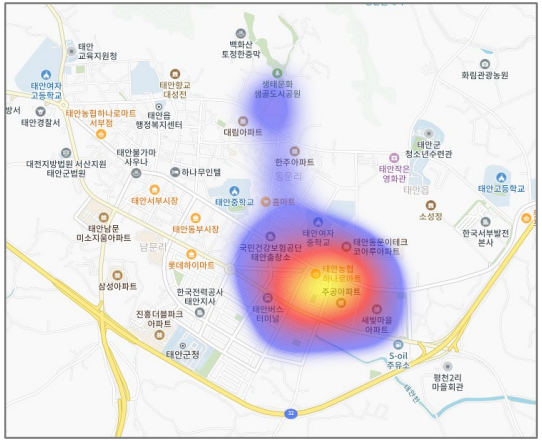
Micro Level

Household / streetscape

Deep Learning Techniques



Detection of Outfoor Fall Risks



2. Resilient Place through Coping Mechanims

Nature Rx Pilot Study

This pilot project focuses on identifying older people's unique challenges and needs when designing nature-based mental health interventions

Collaborating Partners

HEALTH
UNIVERSITY OF UTAH

Madsen Health Center

RED BUTTE GARDEN
THE UNIVERSITY OF UTAH

Mindfulness Training

Nature Walking

https://www.harp.utah.edu/projects/nature-rx-pilot-study

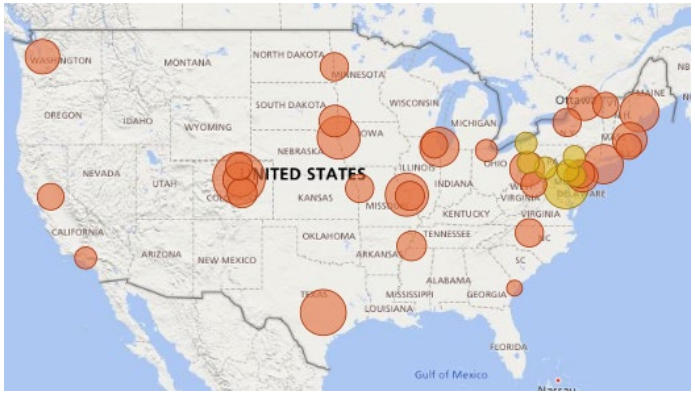
3. Resilient Place through Adaptation

CAPABLE Study

A national study combining handyman services with nursing and occupational therapy to improve mobility and decrease healthcare costs

CAPABLE

35 locations across the country



https://capablenationalcenter.org

4. Resilient Place through Transformation

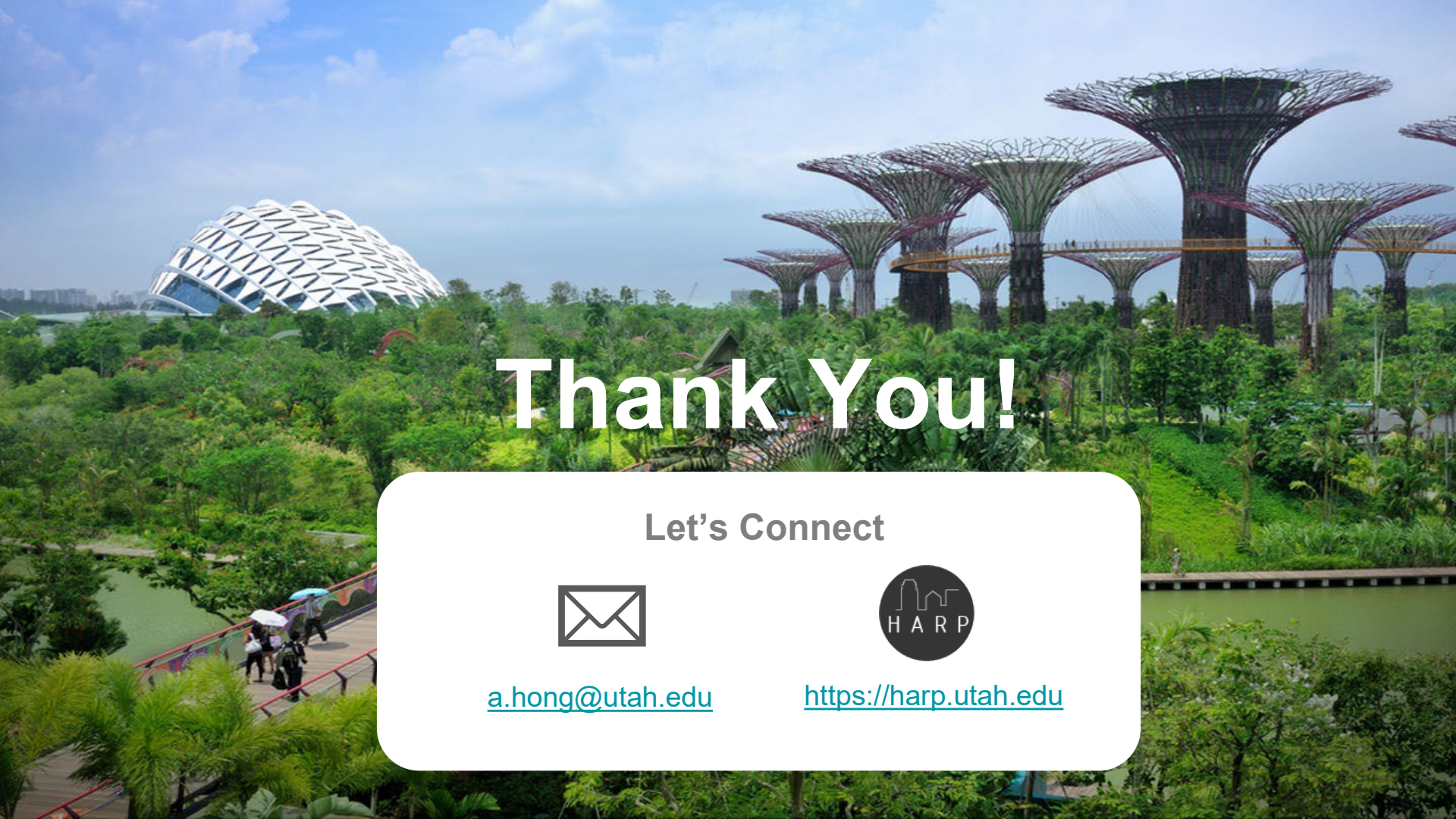
Cobblestone Mat Walking Study

3-month cobblestone walking program led to increasing physical function and decreasing blood pressure compared to conventional walking

Table 2. Outcome Scores by Group at Baseline and Postintervention

Endpoint	Postintervention Mat Walking (n = 54) Mean ± SD	Postintervention Regular Walking (n = 54) Mean ± SD	*P*-value† Group × Time Interaction
Primary			
Functional reach, inches	12.89 ± 2.67	11.17 ± 2.68	.01
Static standing (range 0–4)	3.87 ± 0.39	3.57 ± 0.60	.009
Chair stands, seconds	9.40 ± 2.62	10.98 ± 3.99	<.001
50-foot walk speed, seconds	10.60 ± 2.45	11.62 ± 2.32	.01
Up and Go, seconds	5.87 ± 1.23	6.62 ± 1.65	.14
Systolic blood pressure, mmHg	125.98 ± 13.17	130.97 ± 11.45	.01
Diastolic blood pressure, mmHg	72.83 ± 10.63	74.89 ± 7.63	.008
Secondary			
SF-12 physical component summary score (range 0–100)	66.32 ± 23.77	65.05 ± 19.97	.80
SF-12 mental component summary score (range 0–100)	73.75 ± 18.52	73.42 ± 19.25	.87
Vitality Plus Scale (range 9–45)	36.00 ± 5.69	36.26 ± 5.62	.70

Li et al (2005). *J Am Geriatr Soc, 53(8): 1305-1312*



Thank You!

Let's Connect

a.hong@utah.edu

https://harp.utah.edu

UNIVERSITY of MARYLAND
SCHOOL OF MEDICINE

NEIGHBORHOODS AND RESILIENCE AMONG OLDER ADULTS RECOVERING FROM DISABLING INJURIES AND ILLNESSES

Jason R. Falvey, PT, DPT, PhD
Board Certified Clinical Specialist in Geriatric Physical Therapy
Assistant Professor
Department of Physical Therapy and Rehabilitation Science
Department of Epidemiology and Public Health
University of Maryland School of Medicine
Twitter: @JRayFalvey

Rocky Mountain Regional Geriatrics Conference, 2023

Current Funding

As a Principal Investigator:

- NIA R01AG083173
- NIA K76AG074926 (Paul B. Beeson Emerging Leaders Award)
- NIA P30AG028747 (UMaryland Pepper Center Pilot)
- Donaghue Foundation

As a Co-Investigator:

- NIH/NHLBI R01 HL160822-01
- PCORI

Some work in this talk was also supported by:

- Yale NIA T32AG019134 (PI: Gill, T)
- UMB Institute for Clinical & Translational Research (ICTR) and the National Center for Advancing Translational Sciences (NCATS) Clinical Translational Science Award (CTSA) grant number 1UL1TR003098
- Wadsworth Grant (Internal UMB Funding)
- Foundation for Physical Therapy Research

Disclosures

No other financial disclosures

ENhancing Rehabilitation to Improve Community Health (ENRICH) Lab

Team:

Jason Falvey, PT, DPT, PhD: PI
Lindsey Mathis, PT, DPT: PhD Student
Rhea Mehta, BS: PhD Student
Na Sun, BS: Data Analyst
Jasmine Williams-Cooper, PhD: Qualitative Research Analyst
Chixiang Chen, PhD: Biostatistician

Beeson K76 Mentors:

Jay Magaziner, PhD, MSHyg
Jack Guralnik, MD, PhD
Michelle Shardell, PhD
Daniel Mullins, PhD

Ongoing Work

- Quantitative analysis of neighborhood deprivation and outcomes after fall trauma

- Qualitative evaluation of facilitators and barriers to community mobility among older adults with a new catastrophic disability

Mechanisms of Catastrophic Disability Among Older Adults

- Fall-related hip fracture or head injury
- Critical Illness
- Amputation

Outcomes of Catastrophic Disability Among Older Adults

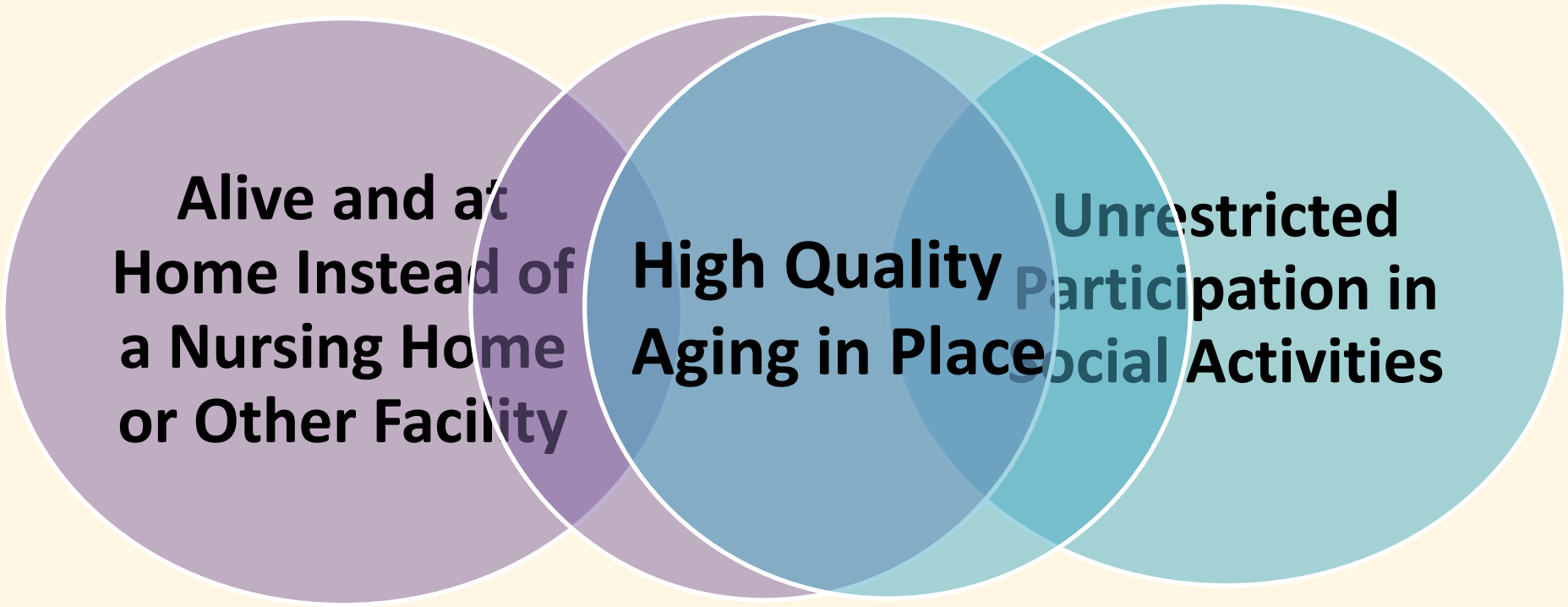
- Incidence of catastrophic disability among older adults is 9.7% (Gill, 2019)

- 38% of non-disabled older adults who experience catastrophic disability do not regain independence (Gill, 2020)

Home Time As a Marker of Resilience

- Days spent at home after injury may be a marker of resilience
- High priority outcome for patients
  - As few as 7 days difference in home time considered meaningful between two hypothetical treatments (Auriemma et al, 2023)
- May prefer to go home with elevated needs versus an institution

From Clinical Outcomes to Community Outcomes

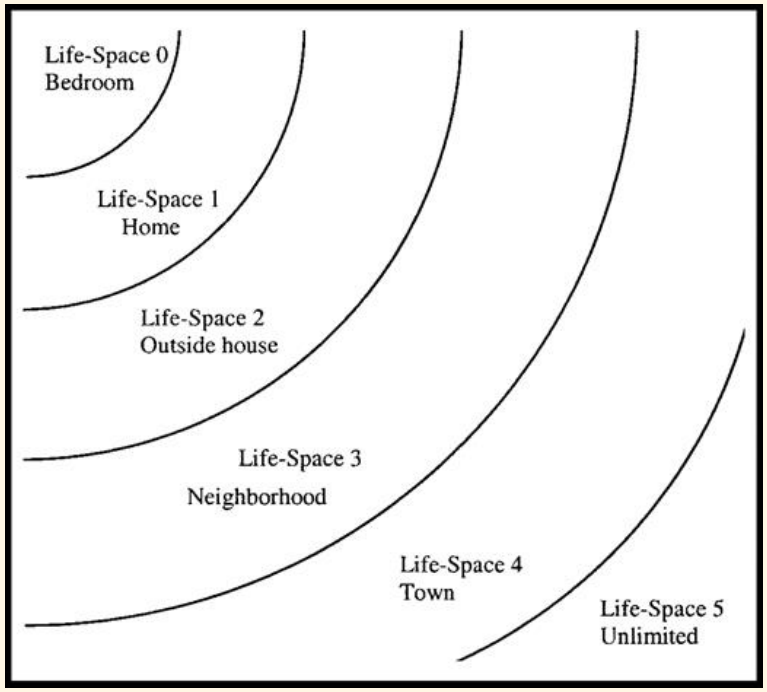


Home but homebound is not good enough!

Community Mobility as a Marker of Resilience After Traumatic Injury

Non-community level mobility

Community level mobility



Community Mobility Demands of Older Adults

<u>Average Distance Walked to Important Destinations Among Older Adults</u>

Doctor: 38 to 64 meters

Pharmacy: 82 to 216 meters

Religious Facility: 48 to 212 meters

Hospital Visitation: 171 to 749 meters

Compare this to 150 foot goal common in post-acute and home health care for older adults

Brown et al, 2010; https://pubmed.ncbi.nlm.nih.gov/20718384/

Community Mobility Demands of Older Adults

Favorite Activities of Community-Dwelling Older Adults

- Walking/jogging (14%)
- Outdoor maintenance (13%)
- Playing sports (8.9%)

https://www.sciencedirect.com/science/article/pii/S0197457214004133#!

Value of Community Mobility to Older Adults with a New Disability

What was one thing outside your home that you were really excited to get back to outside the house?

<u>Participant:</u> "Going to the stores without calling on children. Able to get back on MTA bus without being afraid that I'm going to fall. Just being mobile again is very important to me."

Value of Community Mobility to Older Adults with a New Disability

Okay. How did you feel about getting out to the mobility bus…how did it feel? Did you feel ready to do that?

“I had no other choice. I was not going to stay in the house and pop pills all day. I was not going to become a basket case. I had to get up, I had to get out. I had to do what I had to do”

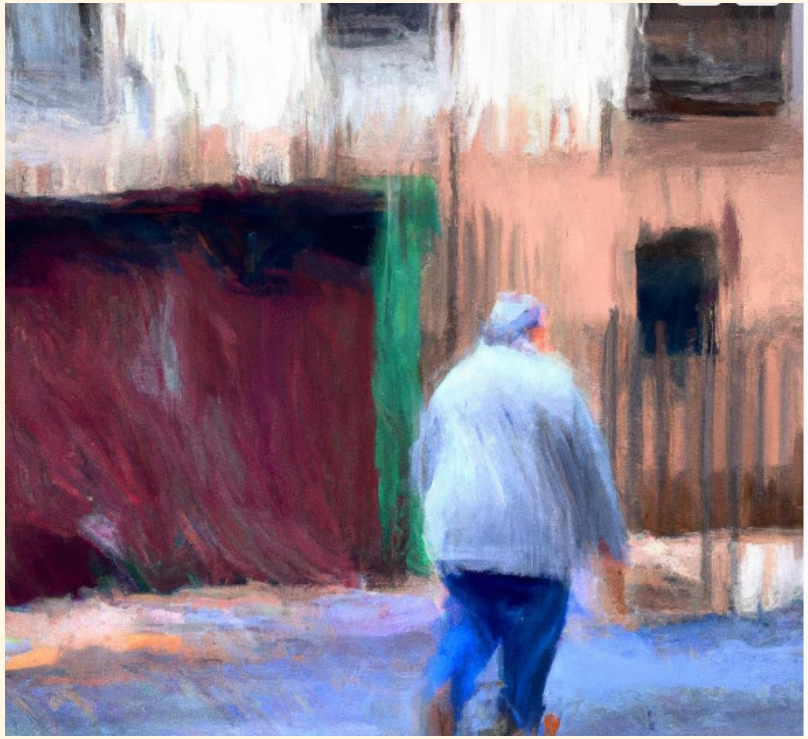
-Participant 3

Community Mobility

25% of older adults cannot walk 2-3 blocks outside unassisted

- 17% can't with a device

1 in 10 older adults lose the ability to walk community distances each year



Hardy, 2004; Mathis et al, in preparation

Implications of Limited Community Mobility

- Inability to walk ¼ mile (2-3 blocks) associated with
  - ~3 fold increase in mortality rates over 1 year
  - 22 more hospitalizations per 100 people

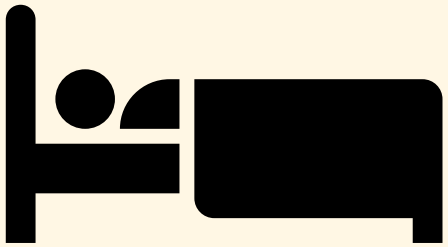
- Limited ability to access public transportation, visit family and friends, attend medical appointments, participant in religious services or clubs

Hardy, 2004; Falvey et al, in preparation

Implications of Limited Community Mobility

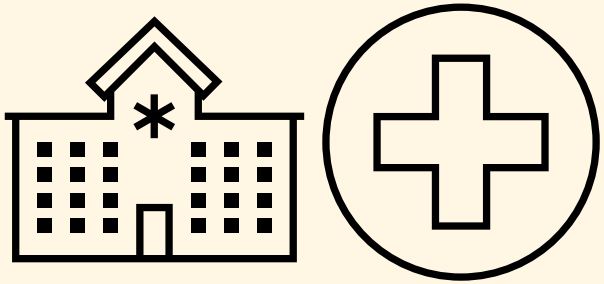
- Less able to relocate during disasters/public health emergencies
  - COVID-19, natural disasters, wildfire smoke*
- Increasing disability, need for caregiver support, and risk for institutionalization
- Social isolation and loneliness (Kuang, 2023)

Precipitants for Community Mobility Loss



Restricted Activity

144% increase in risk



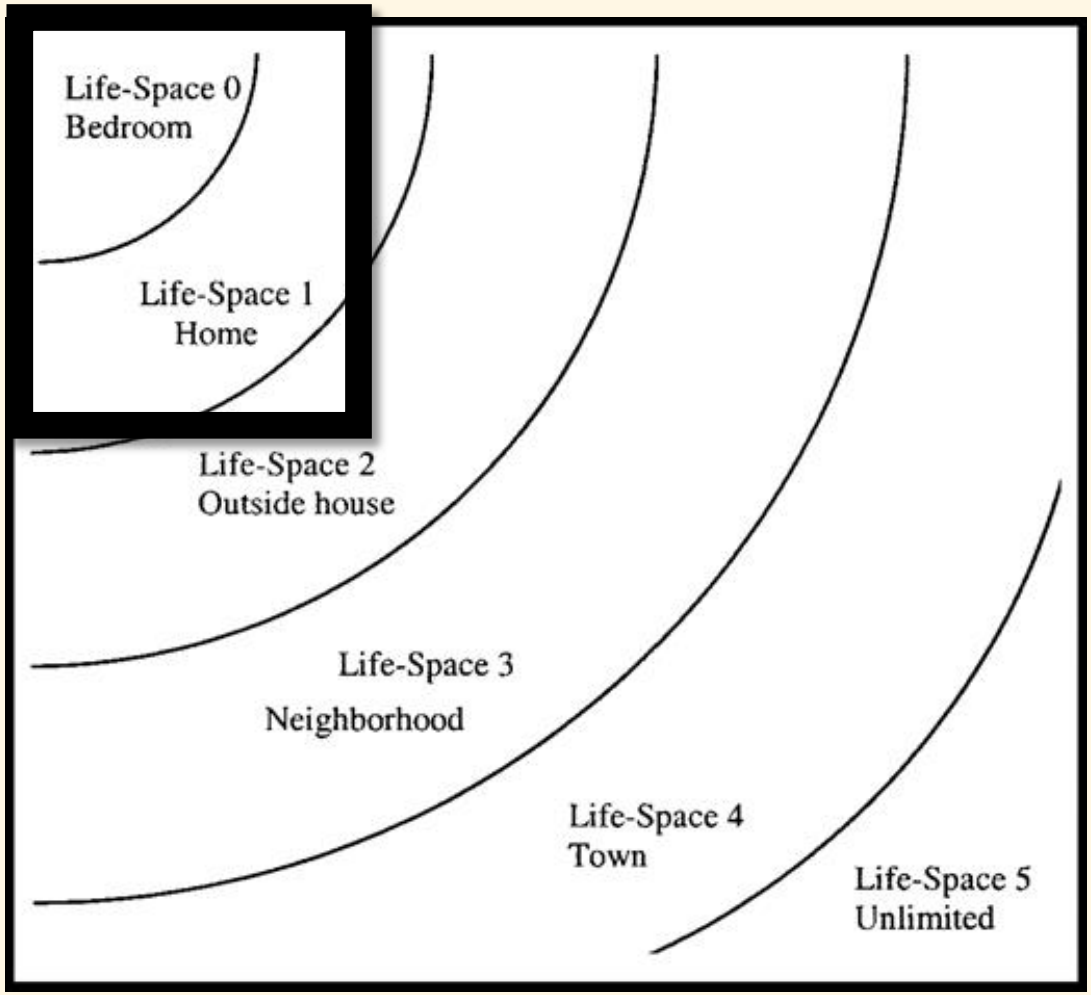
Hospitalization

621% increase in risk

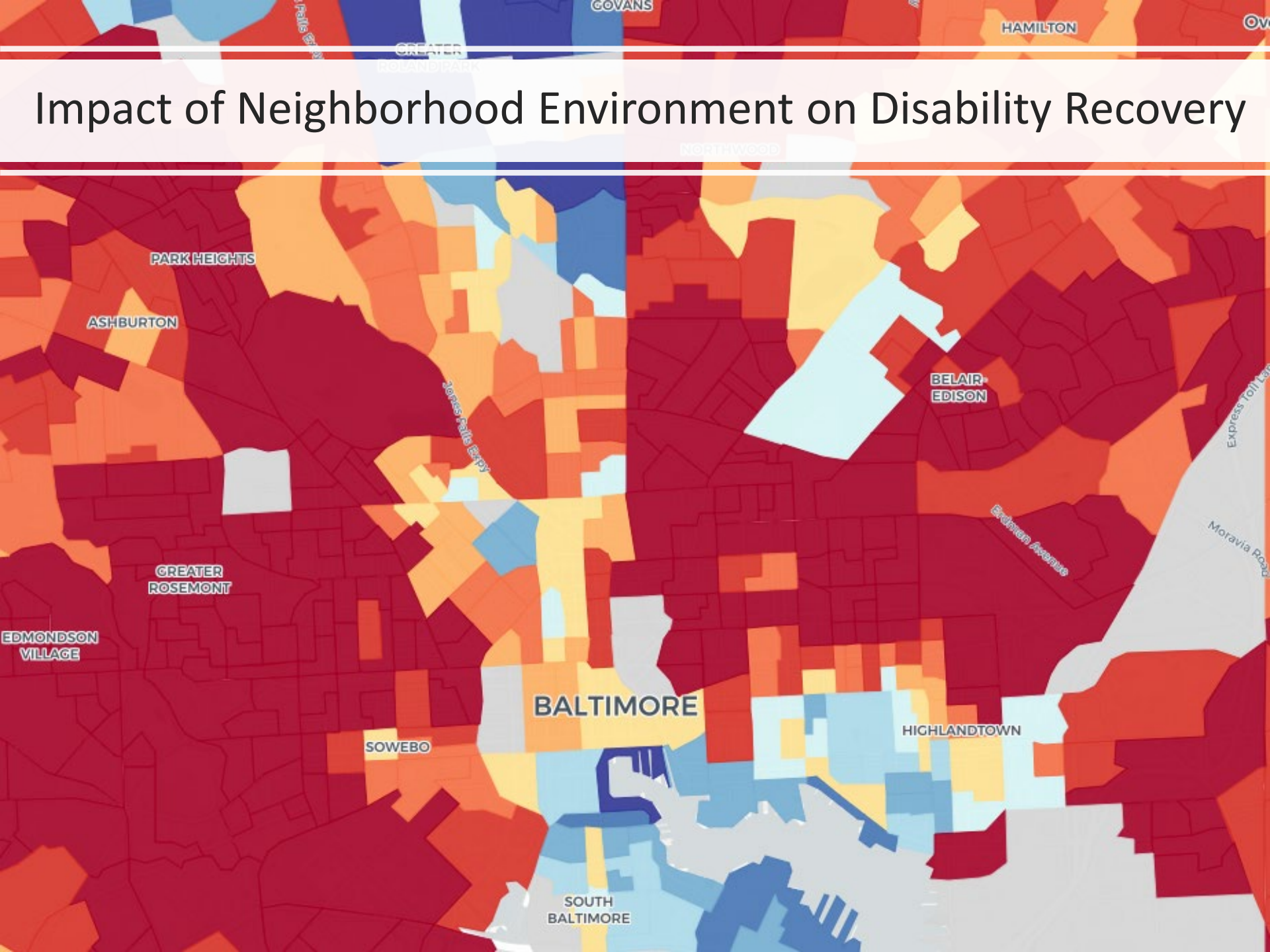
Suggests we do not do a great job of helping people restore community ambulation after acute admissions

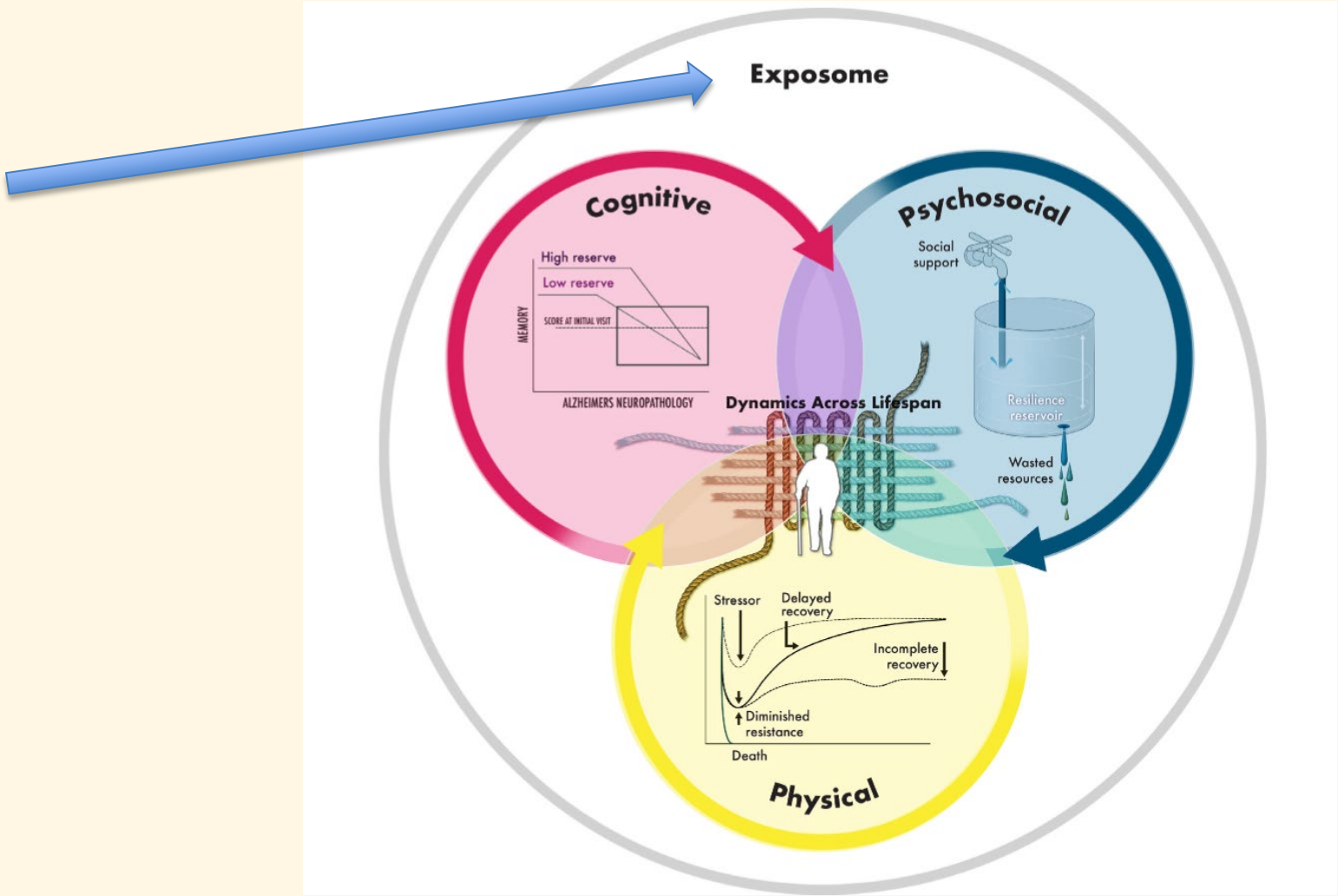
Gill, 2012

Shrinking Life-Space Increases Social Isolation for Older Adults



Impact of Neighborhood Environment on Disability Recovery




Exposome
Cognitive
High reserve
Low reserve
SCORE AT INITIAL VISIT
MEMORY
ALZHEIMERS NEUROPATHOLOGY
Psychosocial
Social support
Resilience reservoir
Wasted resources
Dynamics Across Lifespan
Stressor
Delayed recovery
Incomplete recovery
Diminished resistance
Death
Physical

Major Neighborhood Factors Influencing Resilience

- Built Environment
- Social and Economic Environment
- Access to Healthcare

Built Environment Quality and Mobility

Living in neighborhoods with broken sidewalks, cracks, or curbs:
~4.5 times the odds of mobility disability (inability to walk 2-3 blocks)

https://usa.streetsblog.org/2021/07/28/why-city-sidewalks-still-miss-the-ada-mark/

https://academic.oup.com/aje/article/168/5/506/92998

Built Environment Quality and Mobility

Lack of continuous sidewalks: 27% increase in the odds of being a recurrent faller (Okoye, 2021)

https://usa.streetsblog.org/2021/07/28/why-city-sidewalks-still-miss-the-ada-mark/

Squats Don’t Address Social Determinants of Health!

Older Adult Perspectives on How Built Environment Impacts Community Mobility

"I go 10 blocks out the way on a bus to get to a sidewalk that I can walk on that's not raggedly and that's even. So, yes, I do dumb stuff like that.

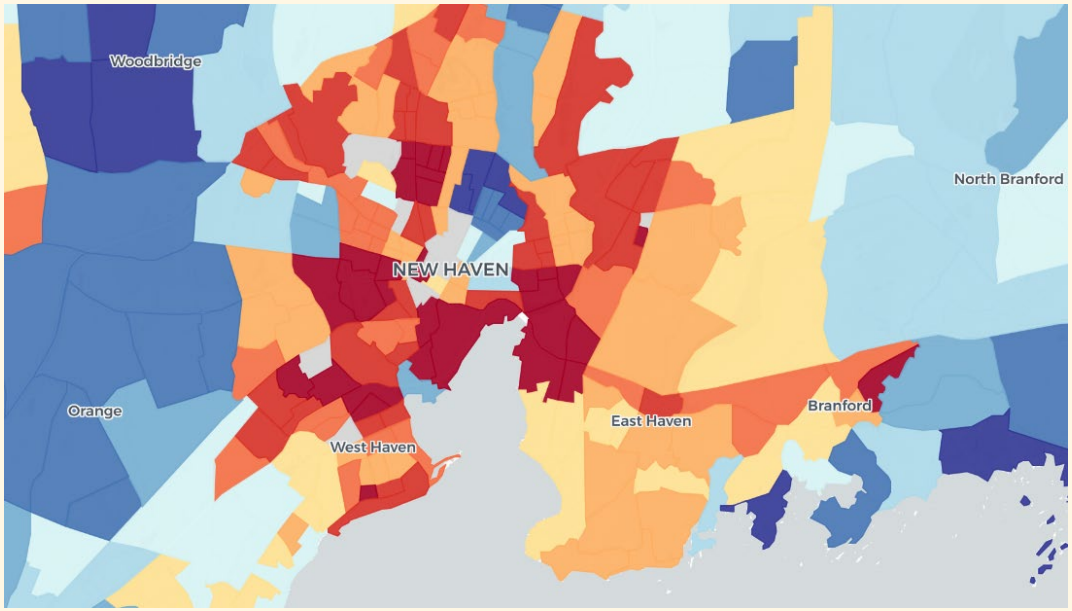
I'll get on a bus and I'll go 10 blocks away so that I can come down on this side of the street instead of walking up on the side of the street that's raggedly."

Neighborhoods and Recovery from Disability

Drew data from Yale Precipitating Events Study (Gill, PI)

Critically ill patients (n=239 admissions) followed for monthly 1 year after admission

Living in a disadvantaged neighborhood: **15% higher** disability burden over 1 year



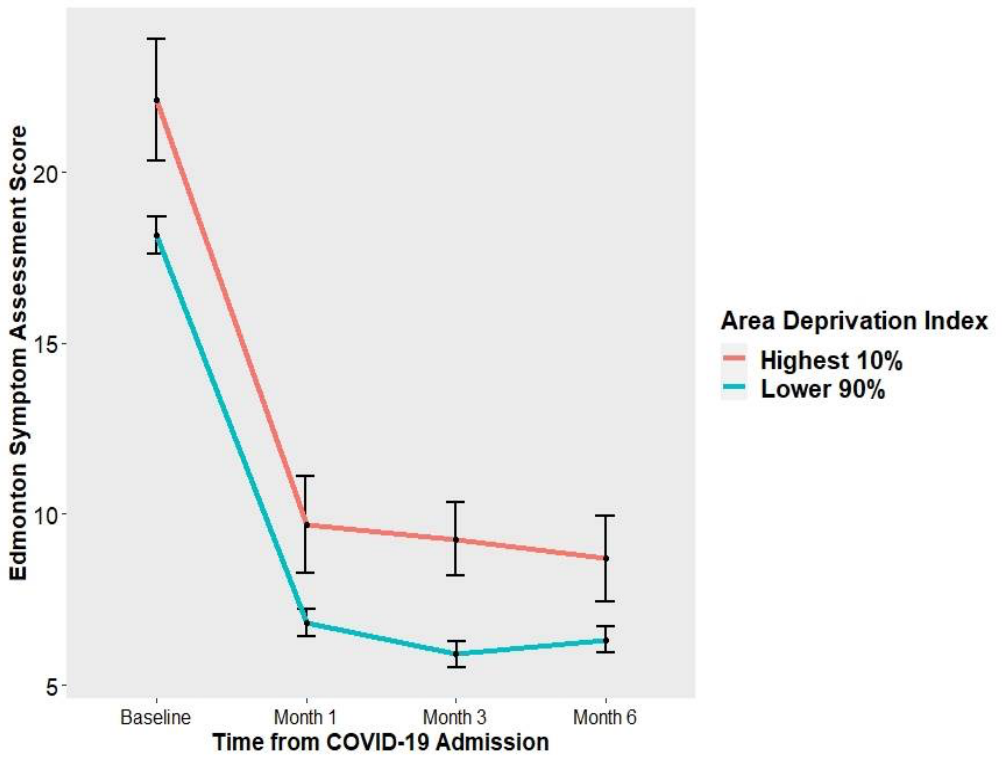
Falvey et al, 2021; Critical Care Medicine

Neighborhoods and Recovery from Disability

Drew data from VALIANT, a cohort study of older COVID survivors (Ferrante/Cohen, mPI)

Older COVID-19 survivors followed for 6 months

Persistently higher symptom burden for older adults



Falvey et al, under review

https://journals.lww.com/ccmjournal/Abstract/9000/Neighborhood_Socioeconomic_Disadvantage_and.95048.aspx

@JRayFalvey

Neighborhood Social Environments

The true meaning of life lies in the connections we forge with others

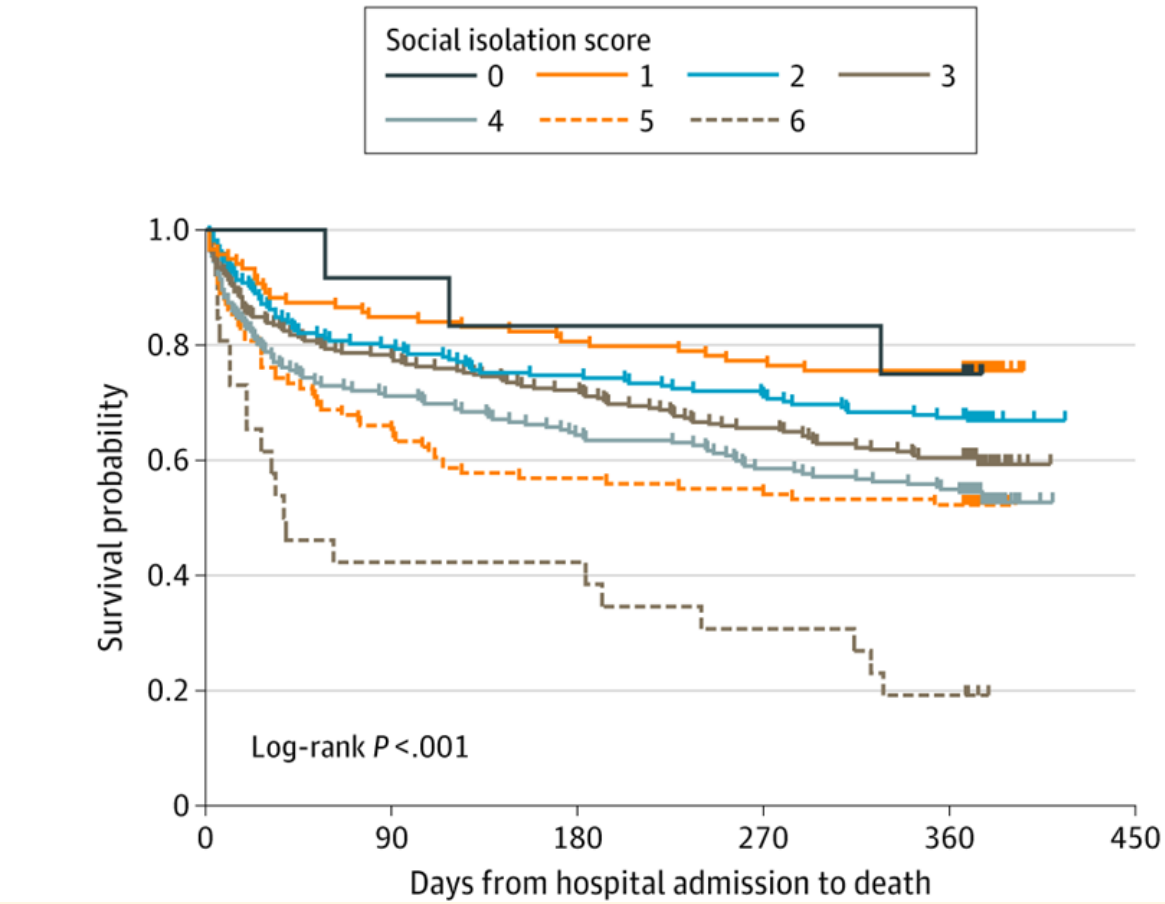
-James Joyce

Neighborhood Social Environments and Resilience After New Disability

- Social connectedness is a critical aspect of recovery after developing a new disability
- Low individual level social connections associated with more post-hospitalization disability (Falvey et al, 2021)
- Low neighborhood cohesion and trust also associated with poorer outcomes

Social Isolation Impedes Recovery From Disabling Hospitalizations

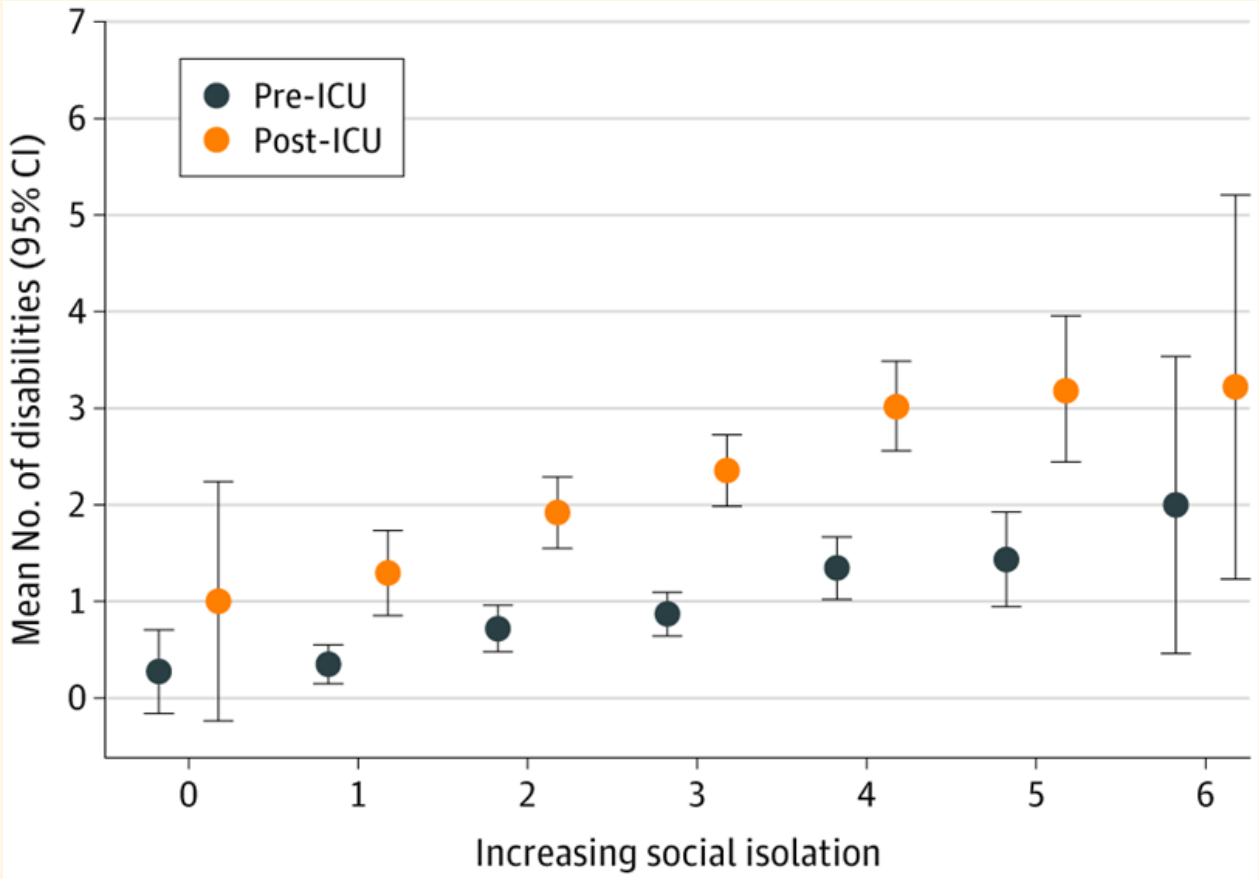
119% elevated risk for death between most and least socially isolated



Falvey et al, JAMA Internal Medicine (2021)

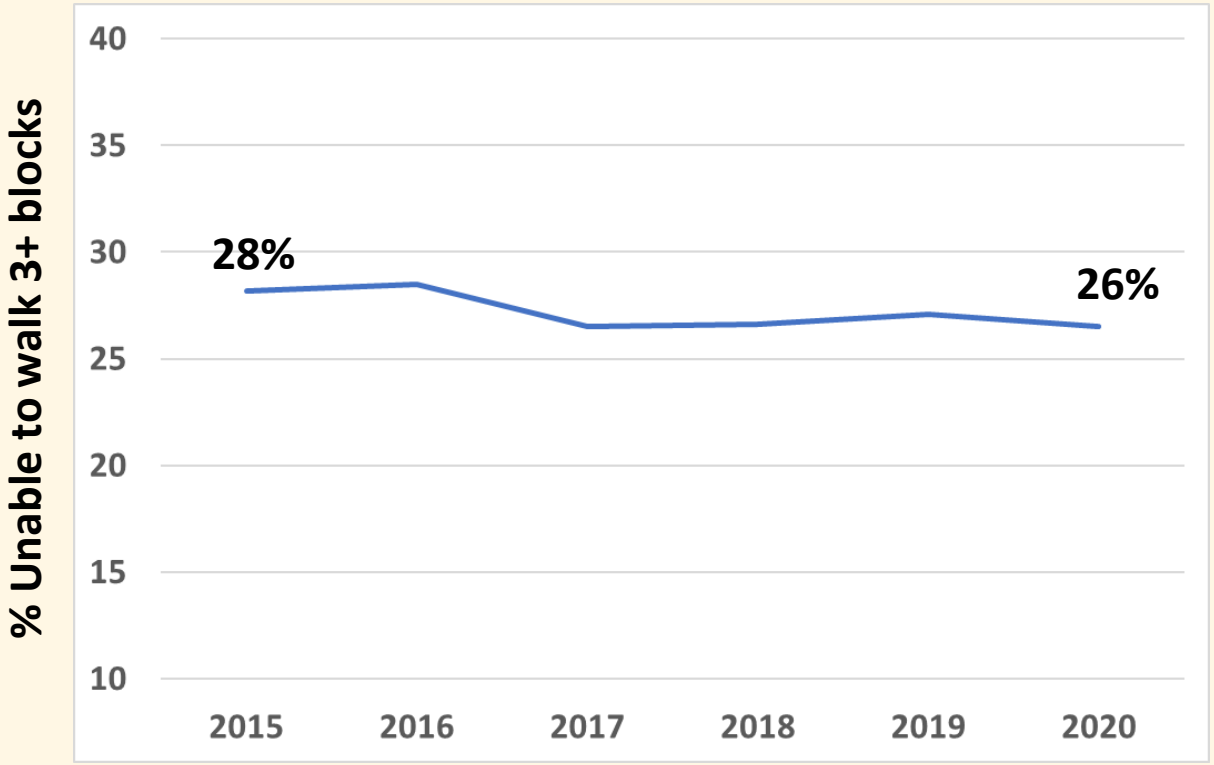
Social Isolation and Disability

50% higher disability burden between most and least socially isolated



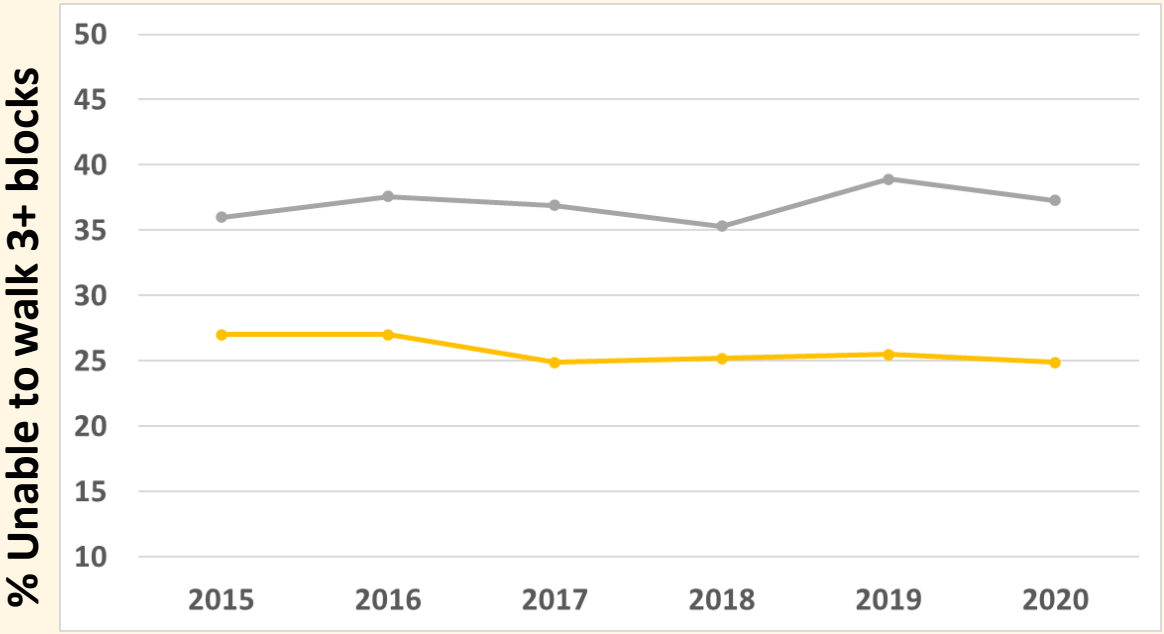
Falvey et al, JAMA IM (2021)

Older Adults Unable to Walk 3 Blocks Independently in the United States, NHATS 2015-2020



Falvey et al, in prep

Low Neighborhood Social Cohesion Impacts Community Mobility



Falvey et al, in prep

Social Cohesion Impacts on Mobility

"I think that my neighbors are great. Luckily I've been in the neighborhood for quite a while and thank goodness. When you build a rapport, I think that's almost essential….So I think that my neighbors have been wonderful."

"If I need a little help coming in the house, if I have too many bags, they're very helpful. I live in a big building with a lot of people, so someone is always there to help."

Importance of Neighborhood Safety

Study Participant #1

"It's just this atmosphere of Baltimore. I'm scared that a bullet don't have no name on it, so I'm just scared"

Falvey et al, in preparation

Importance of Neighborhood Safety

Study Participant #3

"I don't feel like ducking bullets outside. Like I tell people I can't get down no more. I can't run."

Falvey et al, in preparation

Importance of Neighborhood Safety

Study Participant #9

"The store's probably two and a half blocks at least. I can't walk that distance. I'm afraid really to walk that much, because things go on around this block….I'm not in position that where if I was to go out there, that if something, happened I would be a sitting target. There would be no escape for me."

Falvey et al, in preparation

Lower Access to High-Quality Care

Residents of high-poverty zip codes tabulation areas receive lower quality home-based and nursing home care

- Increase in those living in poverty associated with lower quality in SNFs (Park, 2018)
- Readmission rates higher for home health agencies serving a high proportion of patients in low-income areas (Joynt Maddox, 2017)

Lower Access to High-Quality Care

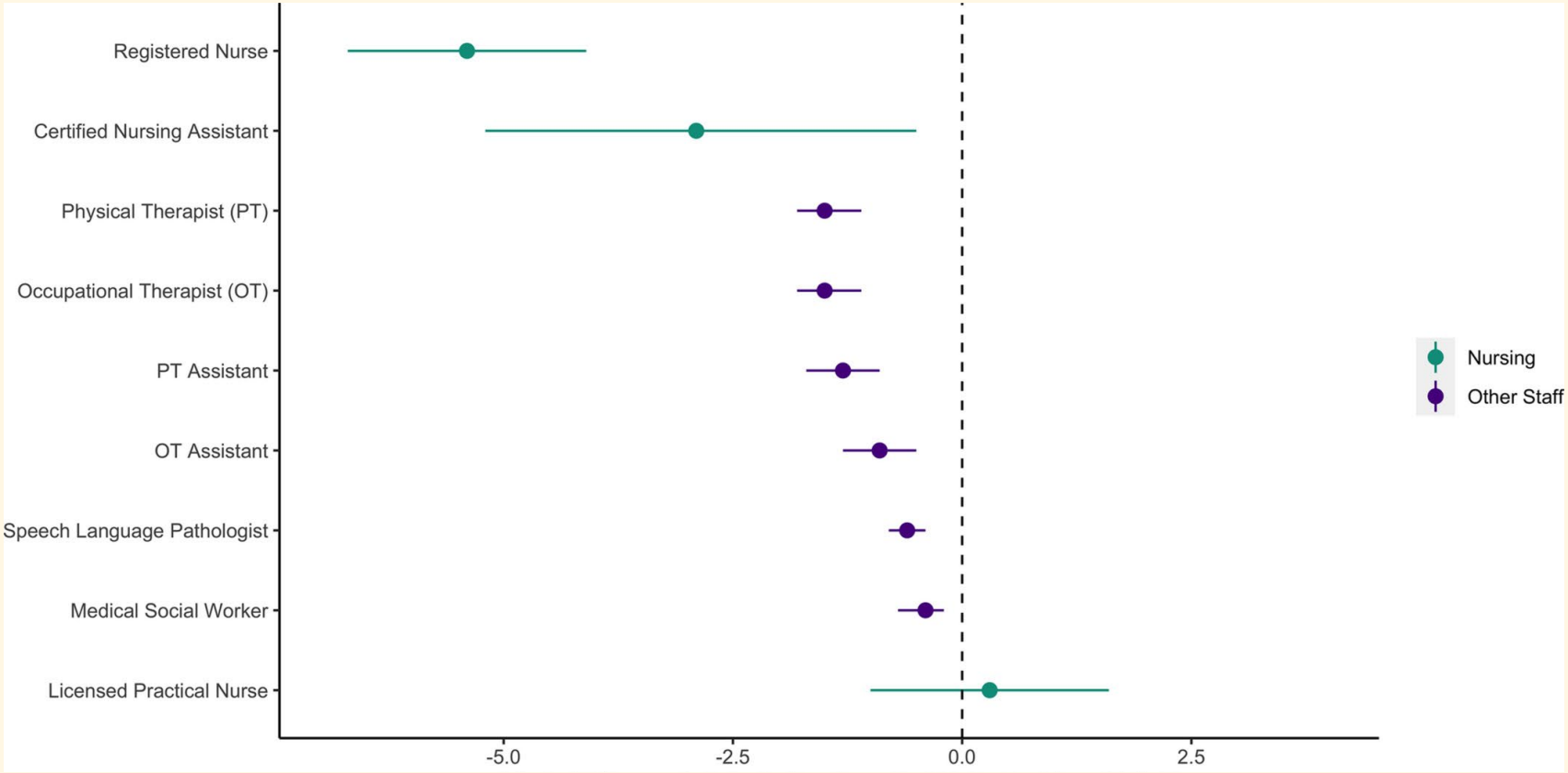
Preliminary work from collaborative work with NYU School of Nursing (Co-PIs Travers/Falvey)

Jasmine Travers, AGPCNP-BC, CCRN, PhD, RN

The Donaghue Foundation

THE PATRICK AND CATHERINE WELDON DONAGHUE MEDICAL RESEARCH FOUNDATION

Staffing in Nursing Homes Located in Disadvantaged Areas



Difference in Hours Worked Relative to More Advantaged Facilities, per 100-patient days

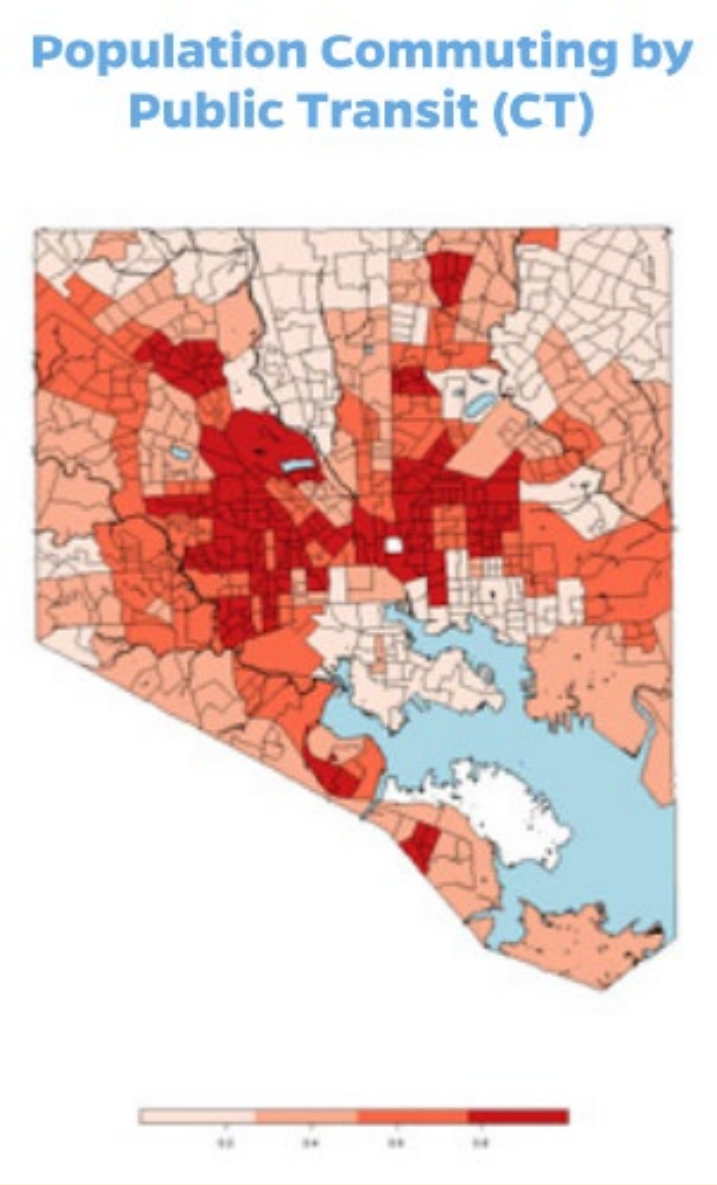
Accessing Outpatient Care Harder in Disadvantaged Neighborhoods

- Nearly 10% of older adults regularly use public transportation (Gimie et al, 2022)
  - 600,000 use public transportation regularly to get to their doctor

Transit Access

~20% of older adults in some urban areas must walk >500 meters to access fixed-route public transit (Clarke et al, 2011)

More transit stops in a neighborhood is associated with better mobility for older adults (Hirsch, 2014)

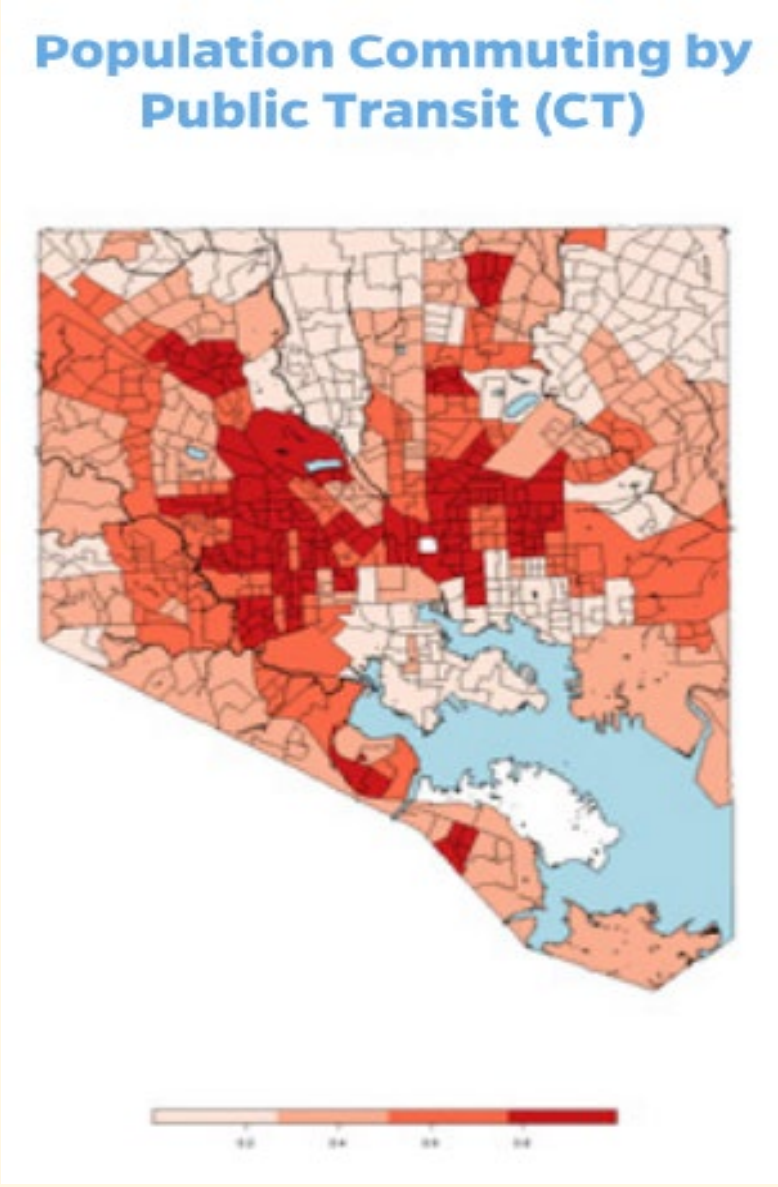


https://americanhealth.jhu.edu/sites/default/files/2021-09/JHU-016%20Transit%20Equity%20Report-FINAL_0.pdf

https://www.sciencedirect.com/science/article/abs/pii/S0277953611001882; https://academic.oup.com/aje/article/180/8/799/2739277

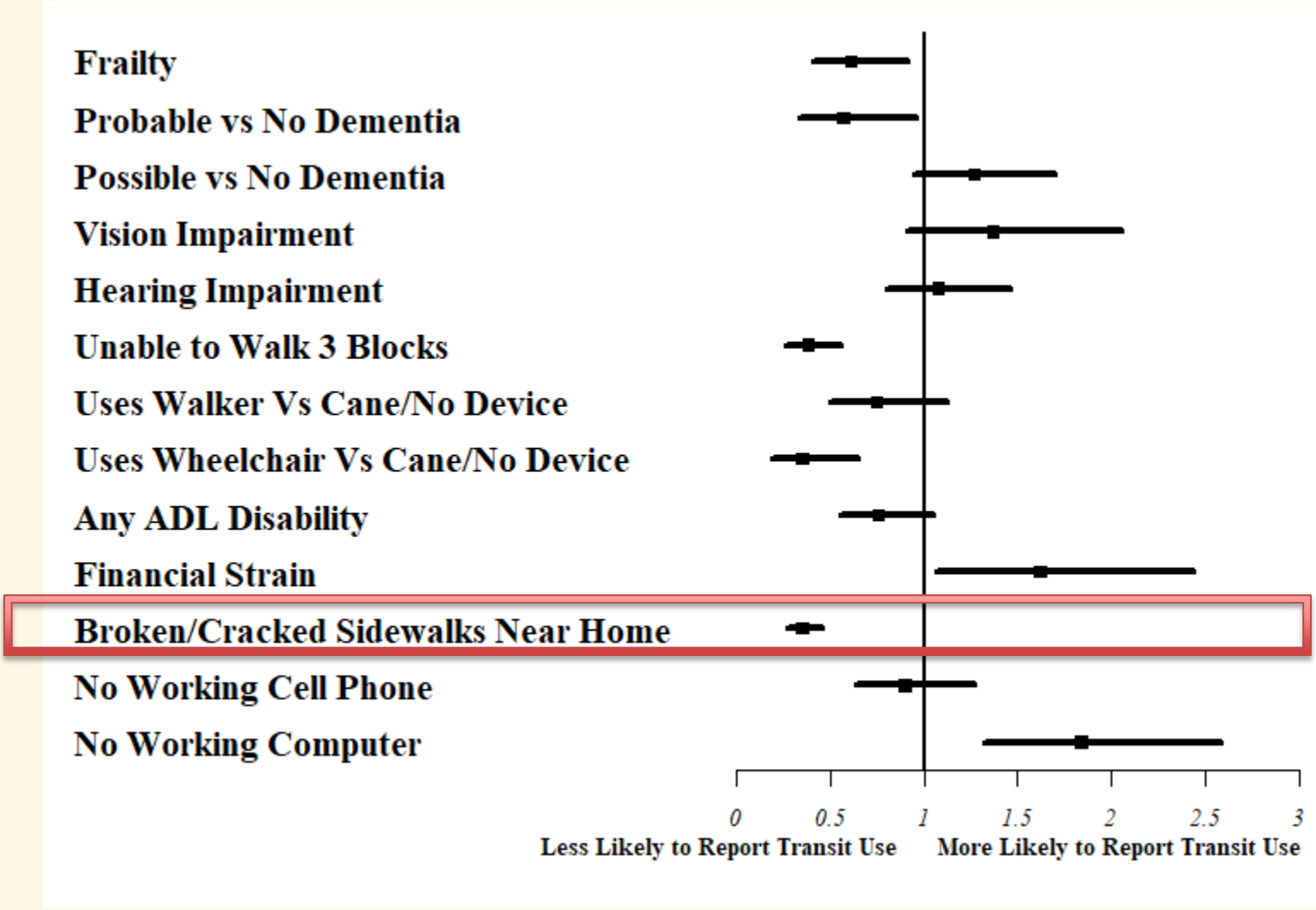
Transit Access

In Baltimore, low transit density is more common in the most economically deprived neighborhoods



https://americanhealth.jhu.edu/sites/default/files/2021-09/JHU-016%20Transit%20Equity%20Report-FINAL_0.pdf

@JRayFalvey



Gimie et al (2022); JAGS 2022

Current Gaps in Rehabilitation Care to Promote Community Mobility

Acute Care and Rehabilitation Settings:

- Minimal outside ambulation for older adults, minimal practice navigating environmental hazards
- Functional outcome tools **max out at 150 feet**
- Rehab not as available in facilities in high-poverty areas

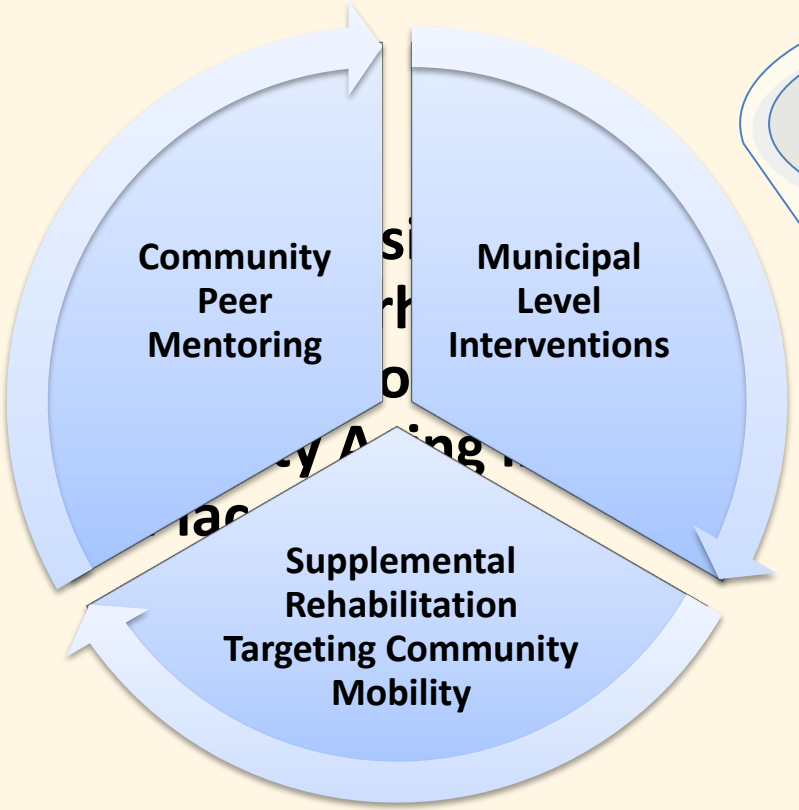
Home Health Care:

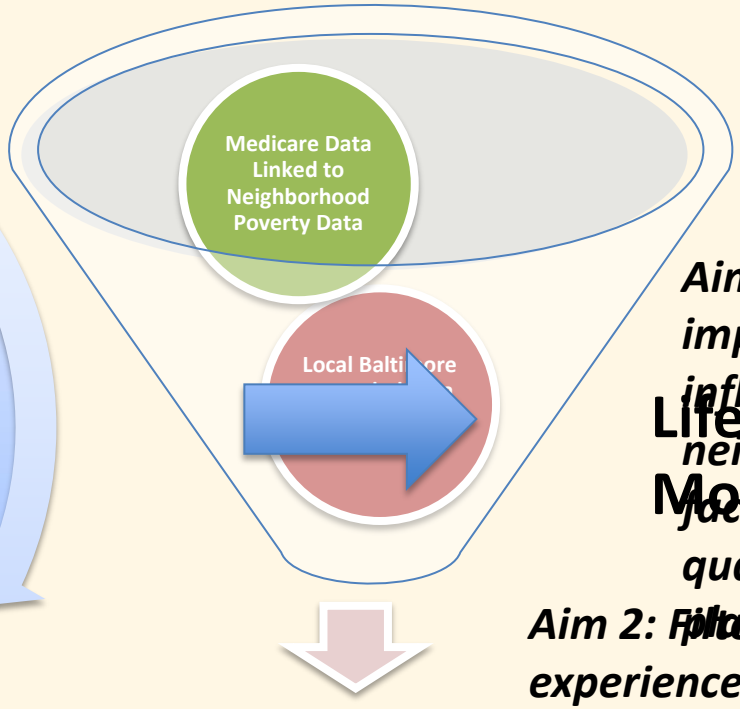
- Homebound requirement for older adults, often leads to artificial barriers on community mobility practice
- Gaps between home health outcomes and demands for outpatient care are high

Outpatient Care:

- Rarely focuses on community mobility, transit access, or other barriers
- Requirements for seeing multiple patients at one time does not allow optimal care
- DME requirements only allow devices for use in home, not community

Moving for Mobility Equity





Life Space Mobility

Aim 1: Evaluate the impact and relative influence of neighborhood factors on high-quality aging in place

Aim 2: Explore through the experiences of community stakeholders

Engaging Community and Municipal Stakeholders to Promote High Quality Aging In Place After Hip Fracture

Take-Home Points

- Community mobility is important to older adults, but not often prioritized in rehabilitation
- Failure to recover community mobility impacts minoritized and vulnerable older adults most
- Interventions should address physical limitations and structural barriers to be maximally effective

Questions

End of Life Care: Transition from CG to Survivorship

Kara Dassel, PhD, FGSA, FAGHE

Rocky Mountain Geriatrics Conference

September 26th, 2023

DISCLOSURES & FUNDING

- I have no business or financial conflicts to disclose.
- Research Funding
  - Center on Aging Pilot Grant
  - Burton Foundation
  - Alzheimer's Association
  - National Institute on Aging

National Institute on Aging

OBJECTIVES

- Importance of advance care planning (ACP)
- Unique aspects of ACP in Alzheimer's disease and Alzheimer's disease-related dementias (AD/ADRD)
- Creation of a dementia ACP planning guide
- Preliminary intervention results & next steps
- Additional ACP resources

ADVANCE CARE PLANNING

ACP is a communication process that empowers adults of any age and any state of health to articulate and share their personal

- values
- life goals, and
- preferences regarding future medical care.[3]

Components:

- Conversations
  - 5 D's (death, decline, diagnosis, divorce, decade)
- Documentation
  - Medical Advance directive
  - Values & preferences
- Revisiting and revising
  - Not static!

BENEFITS OF ACP

Patient

- Reduce unnecessary medical interventions[15-16]
- Lower rate of hospital readmissions[15-16]
- Fewer transitions between health care settings,[15-16]
- Lower end-of-life health care costs[6,17]

Caregiver

- Decreased physical pain and emotional distress
  - Improve subjective well-being[26]
  - Lower burden[19-20]
  - Lower anxiety[24-25]
  - Higher levels of decision-making confidence[27-28]
  - Greater ACP congruence[32-34]

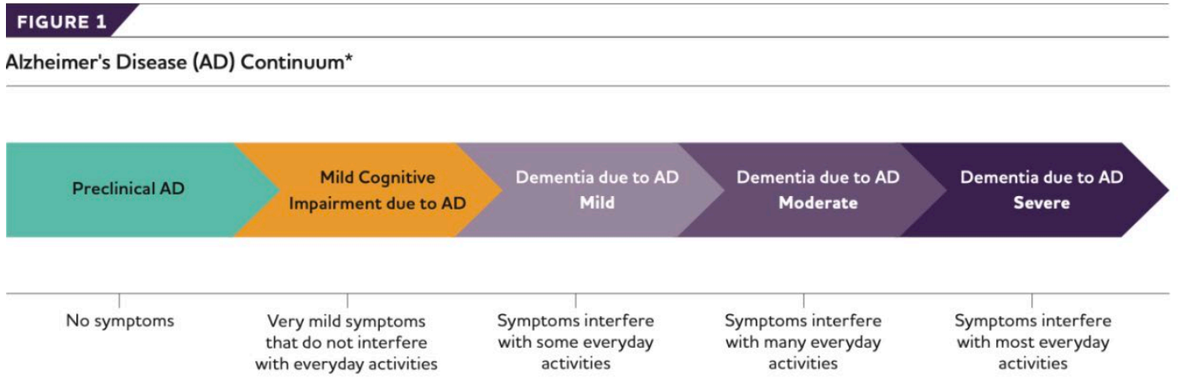
ACP WITHIN THE CONTEXT OF AD/ADRD

Important!

End-of-life health care decisions rely on the substituted judgment of caregivers[5,6] after the PWD loses decision-making abilities.[7-9]

But…less likely to:

- complete an advance directive,[10,11]
- appoint a surrogate decision-maker,[12,13]
- or engage in ACP conversations with family.[14]



2021 Alzheimer's Disease Facts and Figures Report

ACP CAN HELP AVOID STRESS

I wish I knew what mom would want.

I feel so guilty…

I can't put him in a 'home.'

I don't want to be a burden to my family.

If I don't recognize my family, I'm ok to 'go.'

NEED FOR DEMENTIA FOCUSED ACP TOOLS

- Designed for use in specific healthcare settings:
  - primary care,[14, 49-52] nursing homes,[13, 53-57] & hospitals [46, 58, 59]
- Many require a third party to facilitate[51, 52, 60]
- Not theoretically developed or psychometrically validated[61-63]
- Don't promote active engagement in meaningful conversations[60, 64, 65]
- Don't focus on increasing knowledge and competence of the caregiver[40, 42, 66-68]
- Don't focus on decisions across the disease trajectory[24, 69]

MAKING A CASE…

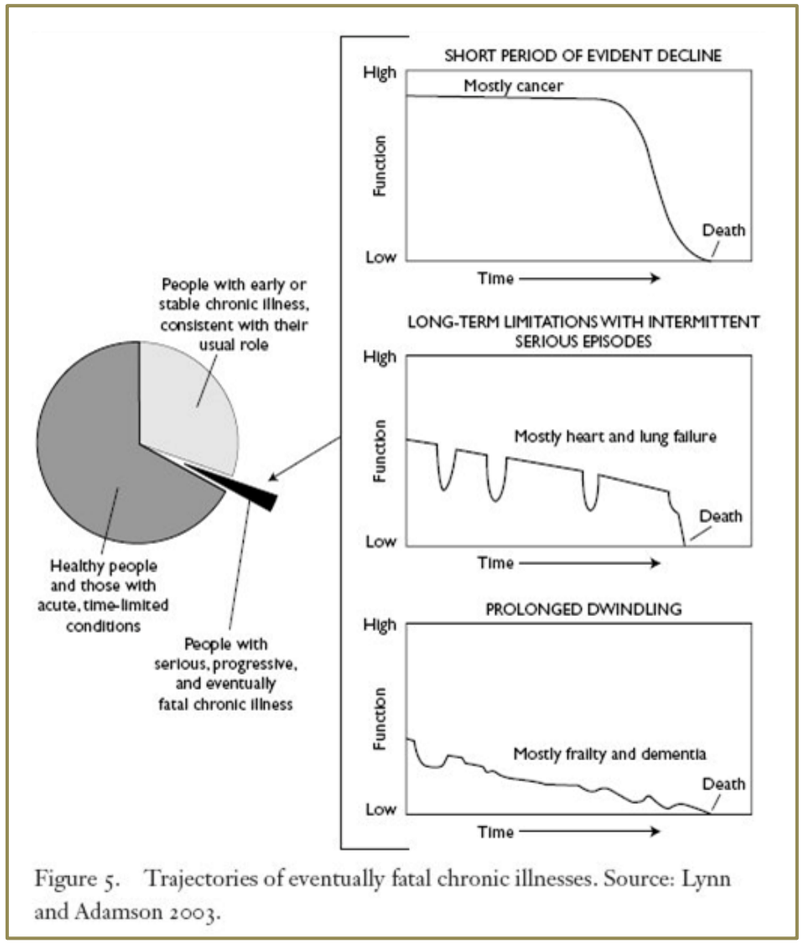


Figure 5. Trajectories of eventually fatal chronic illnesses. Source: Lynn and Adamson 2003.

Clinical Gerontologist

Routledge
Taylor & Francis Group

ISSN: 0731-7115 (Print) 1545-2301 (Online) Journal homepage: http://www.tandfonline.com/loi/wcli20

A Comparison of the Influence of Anticipated Death Trajectory and Personal Values on End-of-Life Care Preferences: A Qualitative Analysis

Katherine P. Supiano PhD, LCSW, Nancy McGee MS, MBA, Kara B. Dassel PhD & Rebecca Utz PhD

Medical Manuscript

The Influence of Hypothetical Death Scenarios on Multidimensional End-of-Life Care Preferences

American Journal of Hospice & Palliative Medicine®
1-8

DOI: 10.1177/1049909116680990
journals.sagepub.com/home/ajh
SAGE

Kara B. Dassel, PhD[1], Rebecca Utz, PhD[2], Katherine Supiano, PhD, LCSW[1], Nancy McGee, MS, MBA[1], and Seth Latimer, MStat[1]

THE LEAD GUIDE

Part 1: End-of-life documents

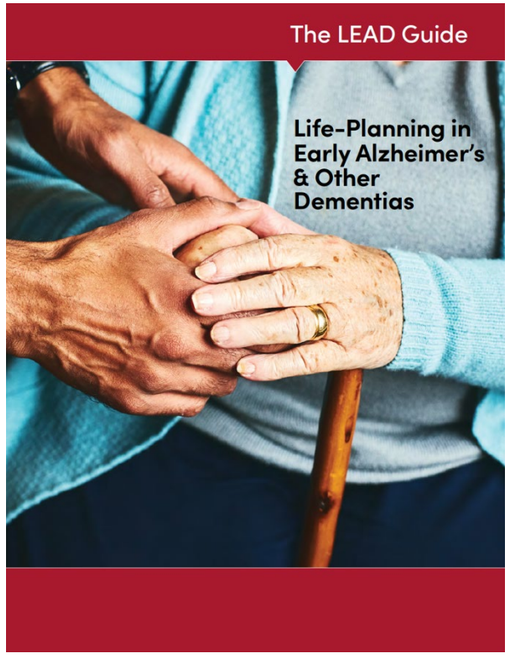
- Living will/advance directive
- DNR
- Medical power of attorney

Part 2: Values

- Quality vs. length of life
- Burden (financial, emotional, physical)
- Decision-making (autonomy vs. shared)

Part 3: Preferences

- Location for ongoing care
- Life-prolonging measures
- Location of death
- Control over the timing of death



Available at:
utahgwep.org
under *Resources*

THE GERONTOLOGICAL SOCIETY OF AMERICA®

Innovation in Aging
cite as: *Innovation in Aging*, 2019, Vol. XX, No. XX, 1–12
doi:10.1093/geroni/igz024
Advance Access publication August 2, 2019

OXFORD

Special Issue: Translational Research on Caregiving: Original Research Article

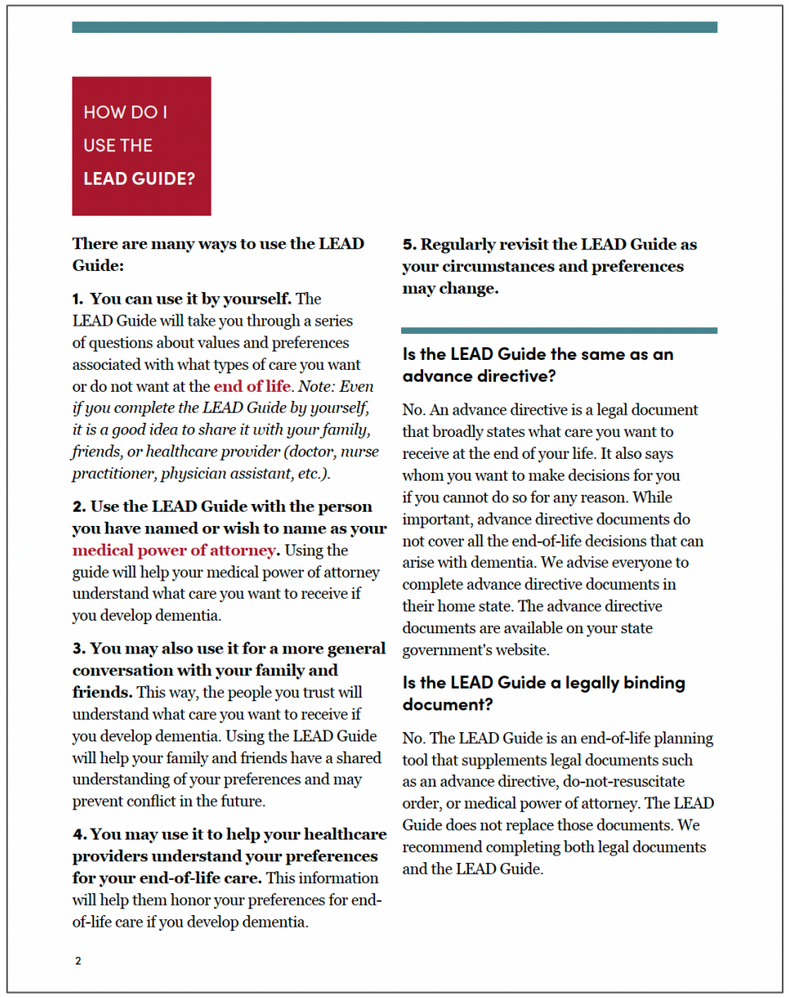
Development of a Dementia-Focused End-of-Life Planning Tool: The LEAD Guide (Life-Planning in Early Alzheimer's and Dementia)

Kara Dassel, PhD,[1,*] Rebecca Utz, PhD,[2] Katherine Supiano, PhD, LCSW, FT,[1] Sara Bybee, LCSW,[1,] and Eli Iacob, PhD[1]

[1]College of Nursing and [2]College of Social and Behavioral Sciences, University of Utah, Salt Lake City.

FOUR WAYS TO COMPLETE THE LEAD GUIDE

1. By yourself
2. With the person you have named or wish to name as your medical power of attorney
3. Use it to guide general conversations about your future care
4. Use it to help your healthcare providers understand your end-of-life wishes



HOW DO I USE THE **LEAD GUIDE?**

There are many ways to use the LEAD Guide:

1. You can use it by yourself. The LEAD Guide will take you through a series of questions about values and preferences associated with what types of care you want or do not want at the **end of life**. *Note: Even if you complete the LEAD Guide by yourself, it is a good idea to share it with your family, friends, or healthcare provider (doctor, nurse practitioner, physician assistant, etc.).*

2. Use the LEAD Guide with the person you have named or wish to name as your medical power of attorney. Using the guide will help your medical power of attorney understand what care you want to receive if you develop dementia.

3. You may also use it for a more general conversation with your family and friends. This way, the people you trust will understand what care you want to receive if you develop dementia. Using the LEAD Guide will help your family and friends have a shared understanding of your preferences and may prevent conflict in the future.

4. You may use it to help your healthcare providers understand your preferences for your end-of-life care. This information will help them honor your preferences for end-of-life care if you develop dementia.

5. Regularly revisit the LEAD Guide as your circumstances and preferences may change.

Is the LEAD Guide the same as an advance directive?

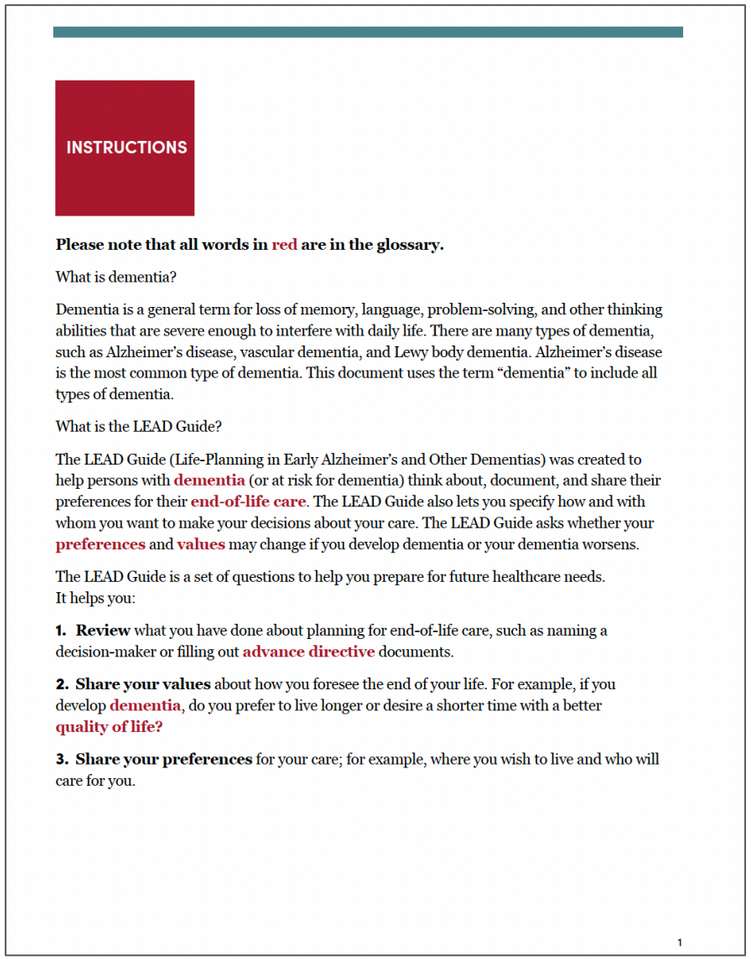
No. An advance directive is a legal document that broadly states what care you want to receive at the end of your life. It also says whom you want to make decisions for you if you cannot do so for any reason. While important, advance directive documents do not cover all the end-of-life decisions that can arise with dementia. We advise everyone to complete advance directive documents in their home state. The advance directive documents are available on your state government's website.

Is the LEAD Guide a legally binding document?

No. The LEAD Guide is an end-of-life planning tool that supplements legal documents such as an advance directive, do-not-resuscitate order, or medical power of attorney. The LEAD Guide does not replace those documents. We recommend completing both legal documents and the LEAD Guide.

2

THREE WAYS THE GUIDE FACILITATES ACP



INSTRUCTIONS

Please note that all words in red are in the glossary.

What is dementia?

Dementia is a general term for loss of memory, language, problem-solving, and other thinking abilities that are severe enough to interfere with daily life. There are many types of dementia, such as Alzheimer's disease, vascular dementia, and Lewy body dementia. Alzheimer's disease is the most common type of dementia. This document uses the term "dementia" to include all types of dementia.

What is the LEAD Guide?

The LEAD Guide (Life-Planning in Early Alzheimer's and Other Dementias) was created to help persons with **dementia** (or at risk for dementia) think about, document, and share their preferences for their **end-of-life care**. The LEAD Guide also lets you specify how and with whom you want to make your decisions about your care. The LEAD Guide asks whether your **preferences** and **values** may change if you develop dementia or your dementia worsens.

The LEAD Guide is a set of questions to help you prepare for future healthcare needs.
It helps you:

1. **Review** what you have done about planning for end-of-life care, such as naming a decision-maker or filling out **advance directive** documents.

2. **Share your values** about how you foresee the end of your life. For example, if you develop **dementia**, do you prefer to live longer or desire a shorter time with a better **quality of life?**

3. **Share your preferences** for your care; for example, where you wish to live and who will care for you.

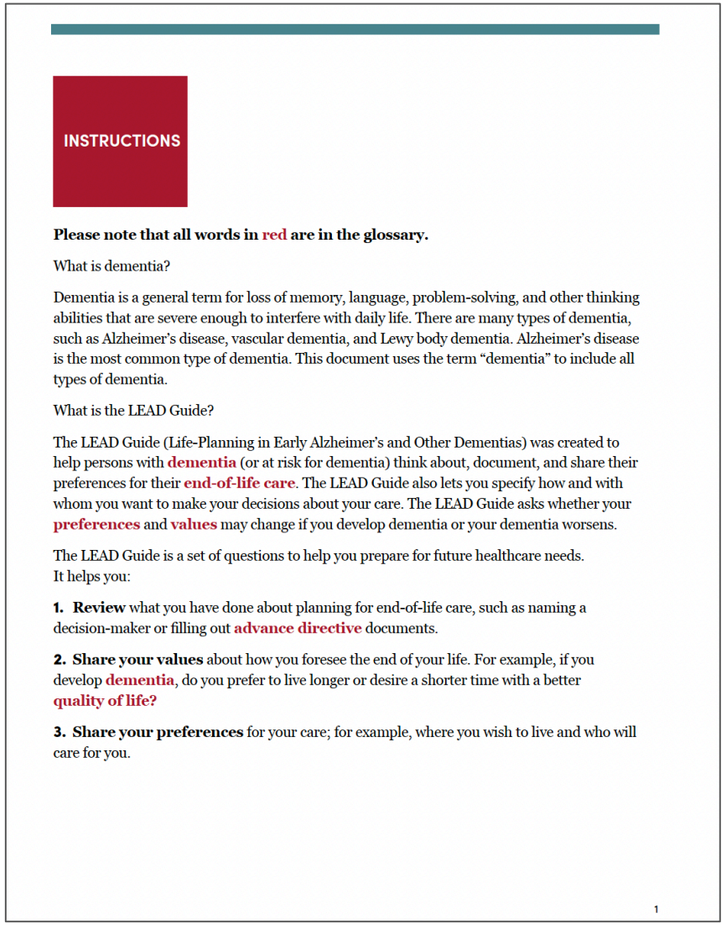
1

1. Review what steps you've taken regarding preparing for your future end-of-life care
2. Share your **values** about how you envision your end-of-life
3. Share your **preferences** for your care at the end of life

PART 1: END-OF-LIFE DOCUMENTATION

Review End-of-Life Documents

1. Advance Directive
2. No Not Resuscitate Order
3. Medical Power of Attorney



INSTRUCTIONS

Please note that all words in red are in the glossary.

What is dementia?

Dementia is a general term for loss of memory, language, problem-solving, and other thinking abilities that are severe enough to interfere with daily life. There are many types of dementia, such as Alzheimer's disease, vascular dementia, and Lewy body dementia. Alzheimer's disease is the most common type of dementia. This document uses the term "dementia" to include all types of dementia.

What is the LEAD Guide?

The LEAD Guide (Life-Planning in Early Alzheimer's and Other Dementias) was created to help persons with **dementia** (or at risk for dementia) think about, document, and share their preferences for their **end-of-life care**. The LEAD Guide also lets you specify how and with whom you want to make your decisions about your care. The LEAD Guide asks whether your **preferences** and **values** may change if you develop dementia or your dementia worsens.

The LEAD Guide is a set of questions to help you prepare for future healthcare needs. It helps you:

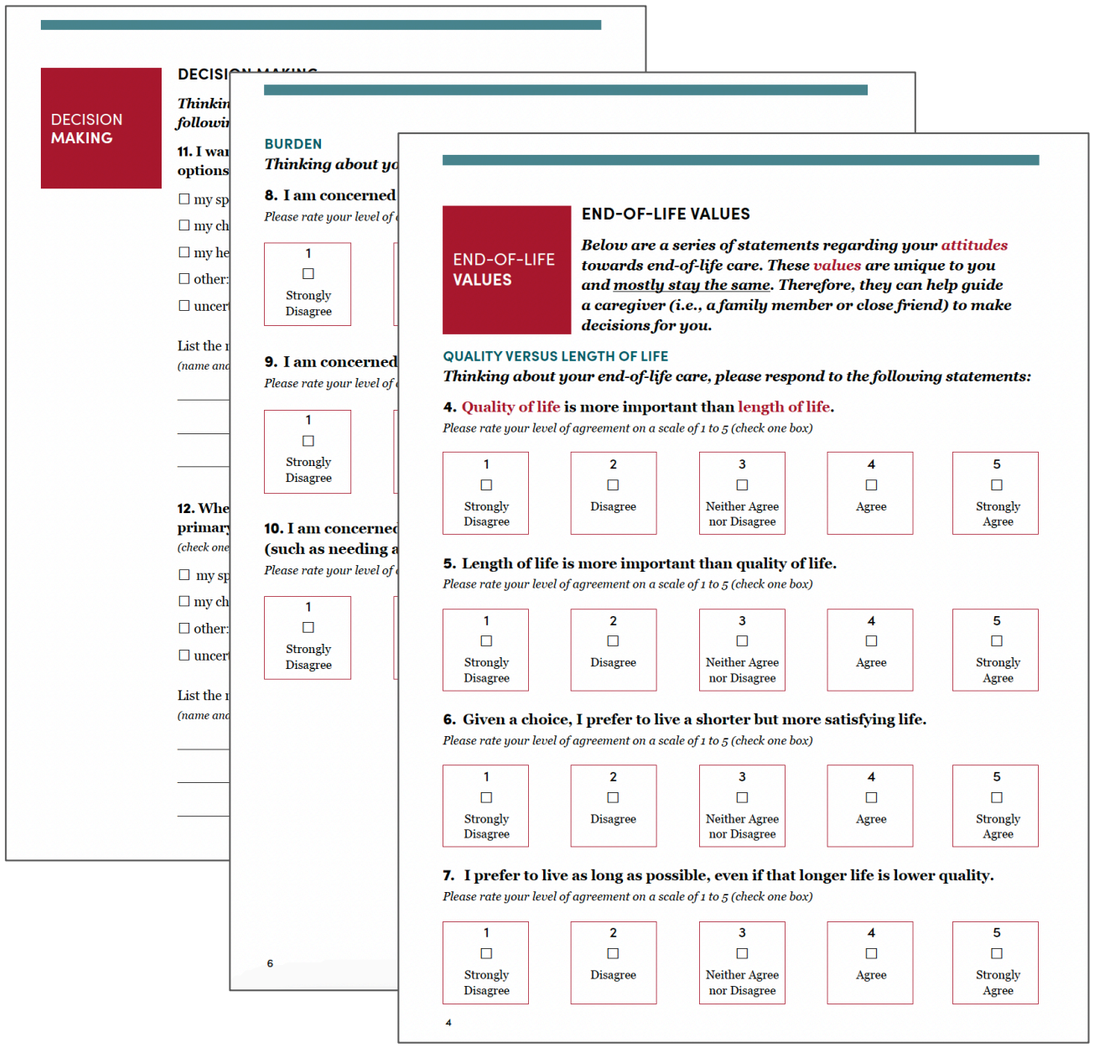
1. **Review** what you have done about planning for end-of-life care, such as naming a decision-maker or filling out **advance directive** documents.

2. **Share your values** about how you foresee the end of your life. For example, if you develop **dementia**, do you prefer to live longer or desire a shorter time with a better **quality of life?**

3. **Share your preferences** for your care; for example, where you wish to live and who will care for you.

1

PART 2: END-OF-LIFE VALUES



Burden

- Financial, emotional, physical

Quality vs. Length of Life

- Importance of each
- Conditional responses
- Open-ended response to define “quality of life”

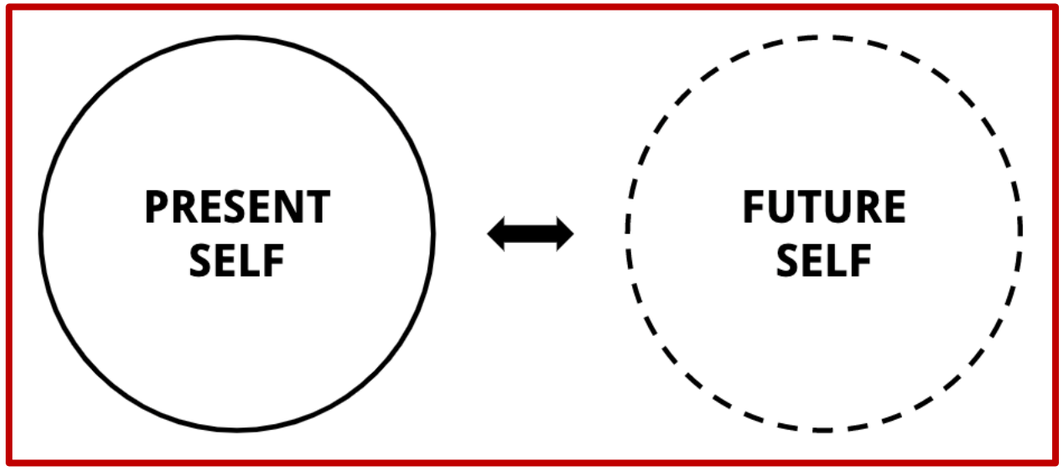
Decision Making

- Self, family, doctor
- Situation specific

PART 3: END-OF-LIFE PREFERENCES

AD/ADRD Trajectory

1) Today, when you can make decisions for yourself
2) Later stages of dementia when decision-making abilities are lost



PART 2: END-OF-LIFE PREFERENCES

Location of care

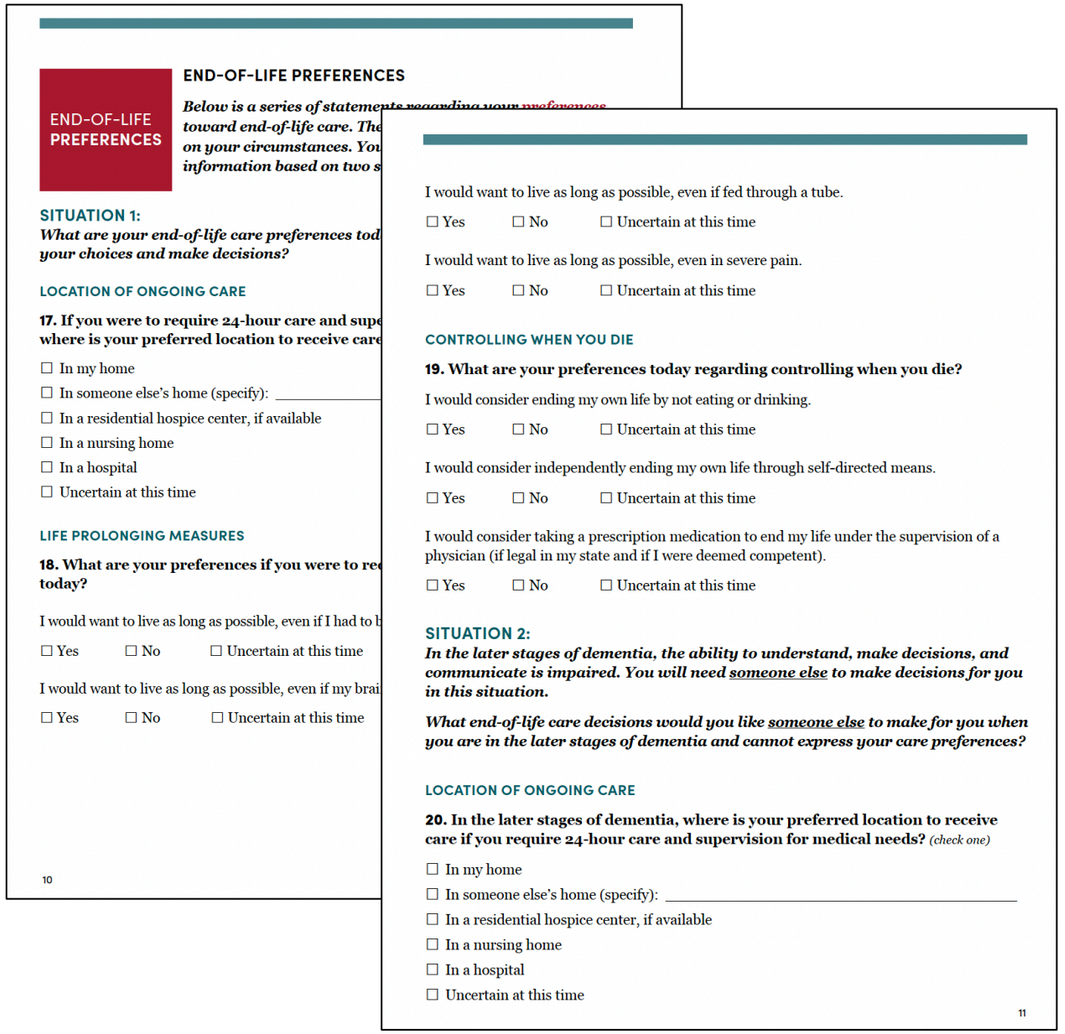
- Nursing home, home, hospice, or hospital

Life-Prolonging Measures

- Feeding tube, ventilator, brain dead, and pain

Controlling the Timing of Death*

- VSED, self-directed, or MAID



END-OF-LIFE PREFERENCES

END-OF-LIFE PREFERENCES

Below is a series of statements regarding your preferences toward end-of-life care. The on your circumstances. You information based on two s

SITUATION 1:

What are your end-of-life care preferences tod your choices and make decisions?

LOCATION OF ONGOING CARE

17. If you were to require 24-hour care and supe where is your preferred location to receive care

- ☐ In my home
- ☐ In someone else's home (specify): _____
- ☐ In a residential hospice center, if available
- ☐ In a nursing home
- ☐ In a hospital
- ☐ Uncertain at this time

LIFE PROLONGING MEASURES

18. What are your preferences if you were to re today?

I would want to live as long as possible, even if I had to l

☐ Yes ☐ No ☐ Uncertain at this time

I would want to live as long as possible, even if my brai

☐ Yes ☐ No ☐ Uncertain at this time

10

I would want to live as long as possible, even if fed through a tube.

☐ Yes ☐ No ☐ Uncertain at this time

I would want to live as long as possible, even in severe pain.

☐ Yes ☐ No ☐ Uncertain at this time

CONTROLLING WHEN YOU DIE

19. What are your preferences today regarding controlling when you die?

I would consider ending my own life by not eating or drinking.

☐ Yes ☐ No ☐ Uncertain at this time

I would consider independently ending my own life through self-directed means.

☐ Yes ☐ No ☐ Uncertain at this time

I would consider taking a prescription medication to end my life under the supervision of a physician (if legal in my state and if I were deemed competent).

☐ Yes ☐ No ☐ Uncertain at this time

SITUATION 2:

In the later stages of dementia, the ability to understand, make decisions, and communicate is impaired. You will need someone else to make decisions for you in this situation.

What end-of-life care decisions would you like someone else to make for you when you are in the later stages of dementia and cannot express your care preferences?

LOCATION OF ONGOING CARE

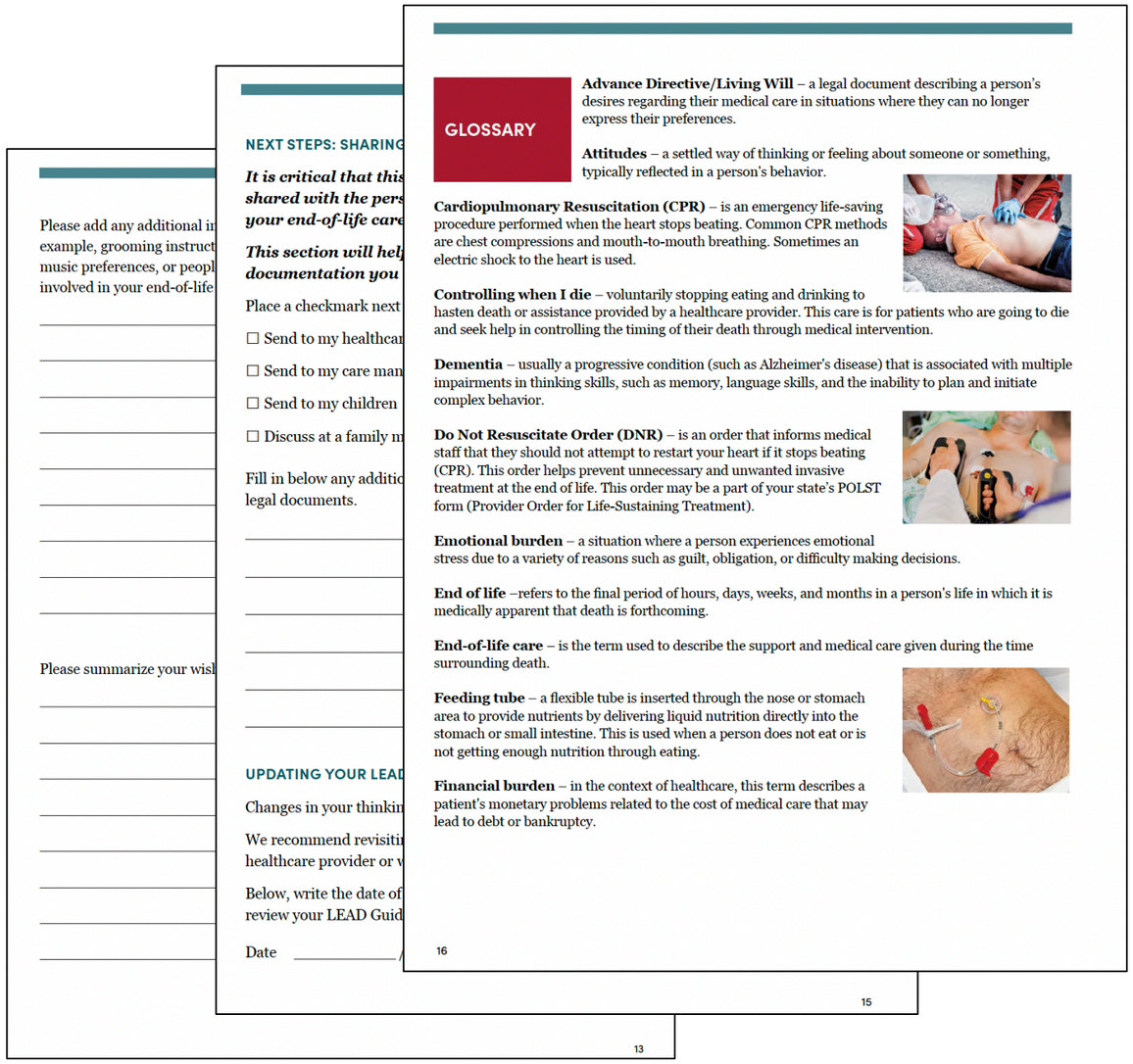
20. In the later stages of dementia, where is your preferred location to receive care if you require 24-hour care and supervision for medical needs? *(check one)*

- ☐ In my home
- ☐ In someone else's home (specify): _____
- ☐ In a residential hospice center, if available
- ☐ In a nursing home
- ☐ In a hospital
- ☐ Uncertain at this time

11

SUPPLEMENTAL INFORMATION

- Summary of wishes
- Additional preferences
- Glossary
- Next steps
  - Share with family & healthcare provider(s)
  - Complete a medical advance directive
  - Update regularly



Please add any additional in
example, grooming instruct
music preferences, or peopl
involved in your end-of-life

Please summarize your wis

13

NEXT STEPS: SHARING

It is critical that this
shared with the pers
your end-of-life care

This section will hel
documentation you

Place a checkmark next

☐ Send to my healthcar
☐ Send to my care man
☐ Send to my children
☐ Discuss at a family m

Fill in below any additic
legal documents.

UPDATING YOUR LEAD

Changes in your thinkin

We recommend revisiti
healthcare provider or v

Below, write the date of
review your LEAD Guid

Date ____/

15

GLOSSARY

Advance Directive/Living Will – a legal document describing a person's desires regarding their medical care in situations where they can no longer express their preferences.

Attitudes – a settled way of thinking or feeling about someone or something, typically reflected in a person's behavior.

Cardiopulmonary Resuscitation (CPR) – is an emergency life-saving procedure performed when the heart stops beating. Common CPR methods are chest compressions and mouth-to-mouth breathing. Sometimes an electric shock to the heart is used.

Controlling when I die – voluntarily stopping eating and drinking to hasten death or assistance provided by a healthcare provider. This care is for patients who are going to die and seek help in controlling the timing of their death through medical intervention.

Dementia – usually a progressive condition (such as Alzheimer's disease) that is associated with multiple impairments in thinking skills, such as memory, language skills, and the inability to plan and initiate complex behavior.

Do Not Resuscitate Order (DNR) – is an order that informs medical staff that they should not attempt to restart your heart if it stops beating (CPR). This order helps prevent unnecessary and unwanted invasive treatment at the end of life. This order may be a part of your state's POLST form (Provider Order for Life-Sustaining Treatment).

Emotional burden – a situation where a person experiences emotional stress due to a variety of reasons such as guilt, obligation, or difficulty making decisions.

End of life –refers to the final period of hours, days, weeks, and months in a person's life in which it is medically apparent that death is forthcoming.

End-of-life care – is the term used to describe the support and medical care given during the time surrounding death.

Feeding tube – a flexible tube is inserted through the nose or stomach area to provide nutrients by delivering liquid nutrition directly into the stomach or small intestine. This is used when a person does not eat or is not getting enough nutrition through eating.

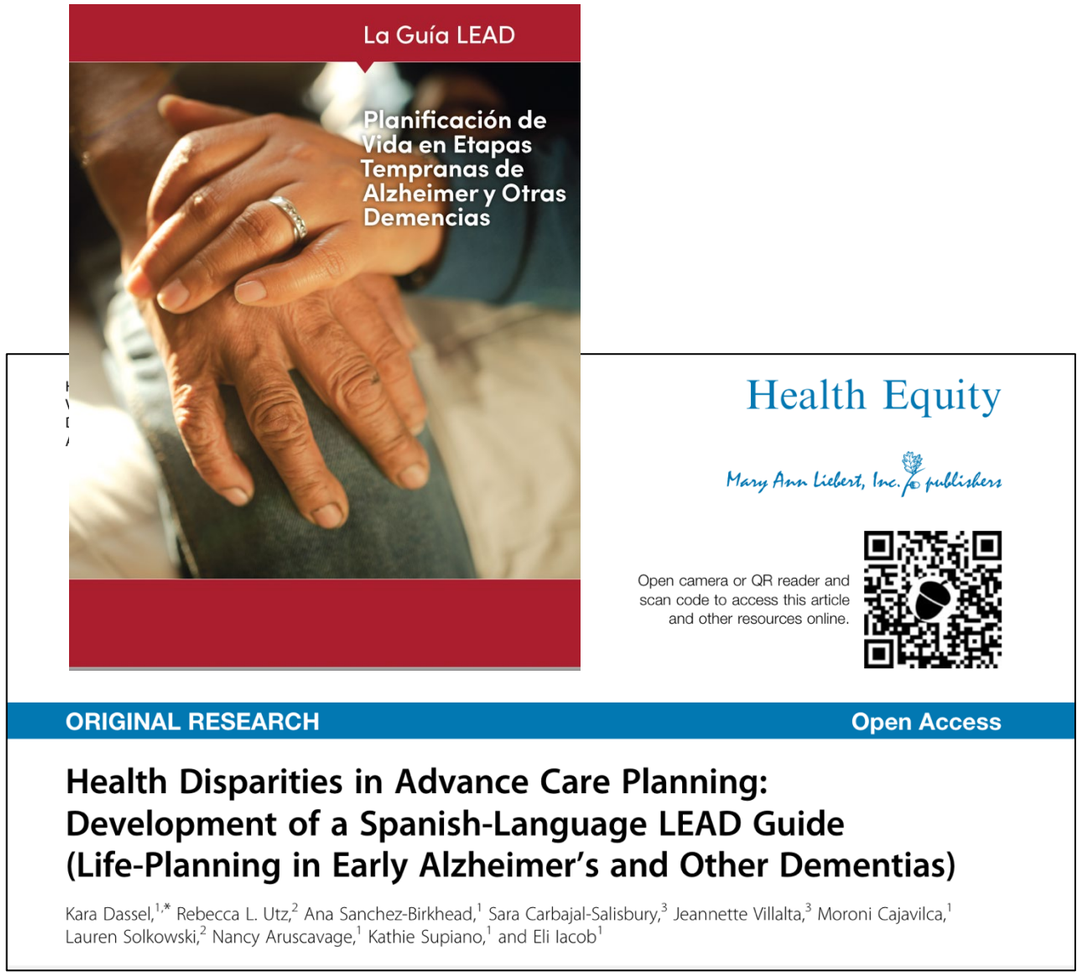
Financial burden – in the context of healthcare, this term describes a patient's monetary problems related to the cost of medical care that may lead to debt or bankruptcy.

16

NEW SPANISH LEAD GUIDE!

In collaboration with Alliance Community

- Culturally adapted
- Translated
- Next steps
  - Pilot intervention in Hispanic/Latino community-based AD/ADRD population



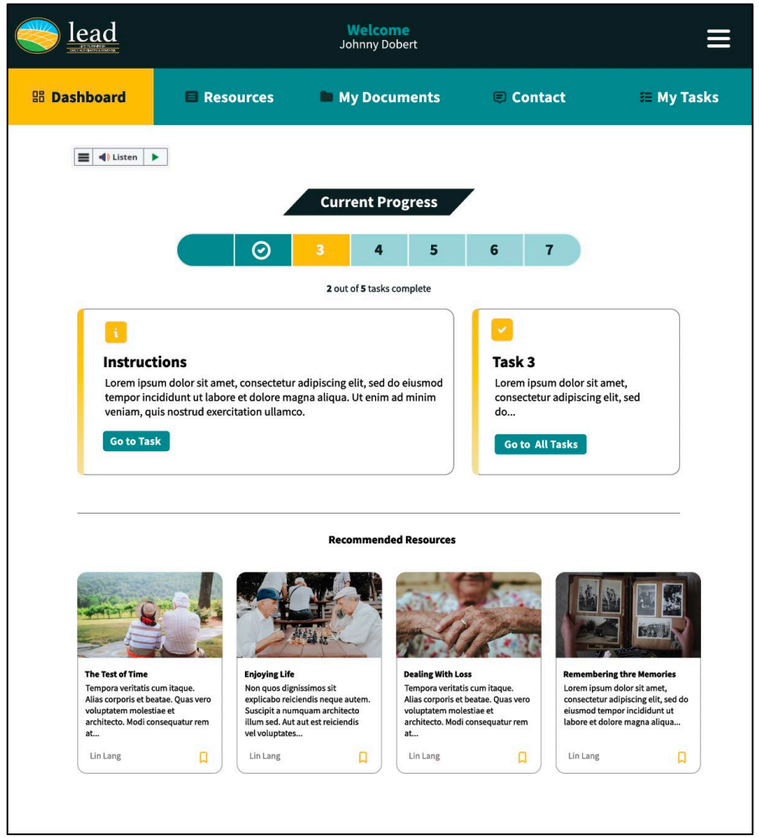
DOES THE LEAD GUIDE "WORK"?

- N=51 dyads
- Decision-making self-efficacy scores improved
- Relationship strain declined
- ACP concordance improved

The LEAD Intervention is a **feasible** and **effective** platform to promote ACP planning in community-based AD/ADRD dyads

NEXT STEPS: WEB-BASED CLINICAL TRIAL

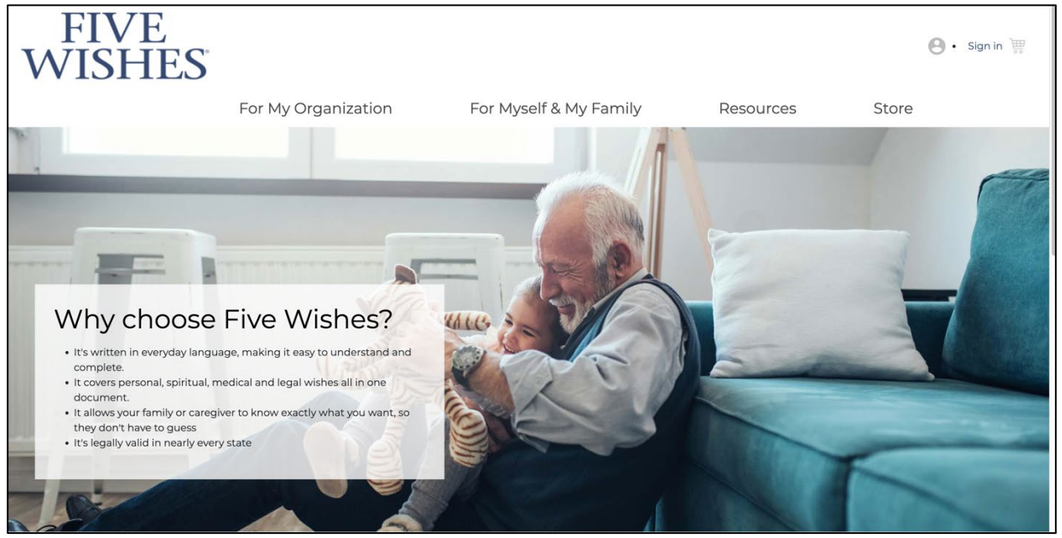
- 5-year clinical trial
- 20-week self-administered web-based ACP intervention
- + Outcomes: subjective well-being and anxiety
- Community-based AD/ADRD dyads
  - Recruitment begins January 2024
  - lead@utah.edu

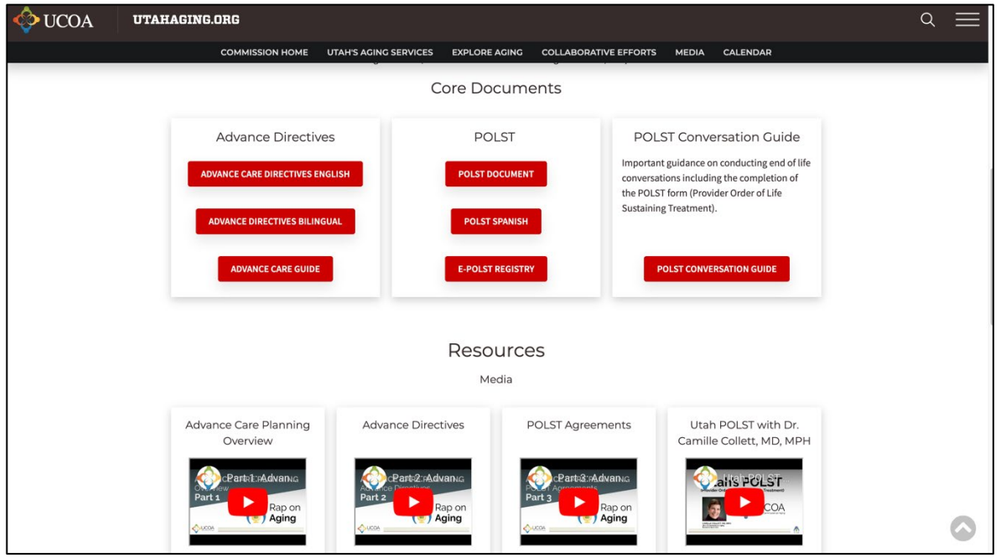


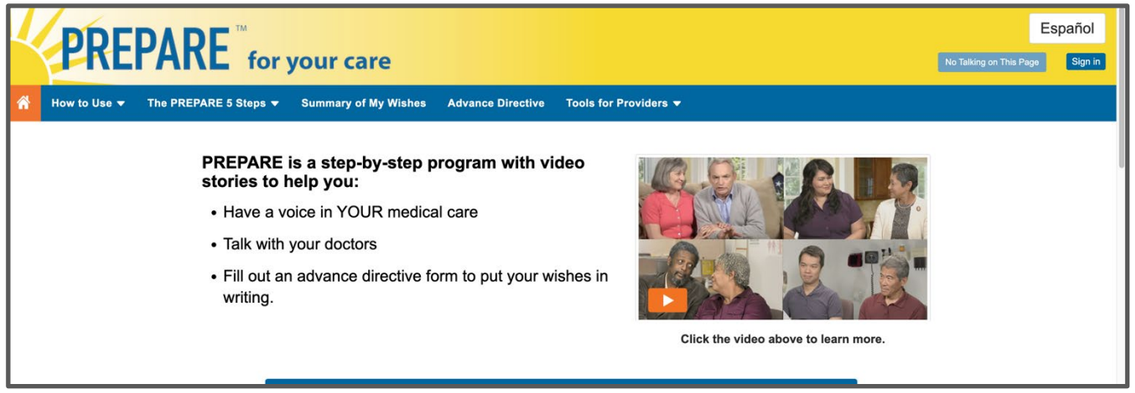
IN SUMMARY, THE LEAD GUIDE

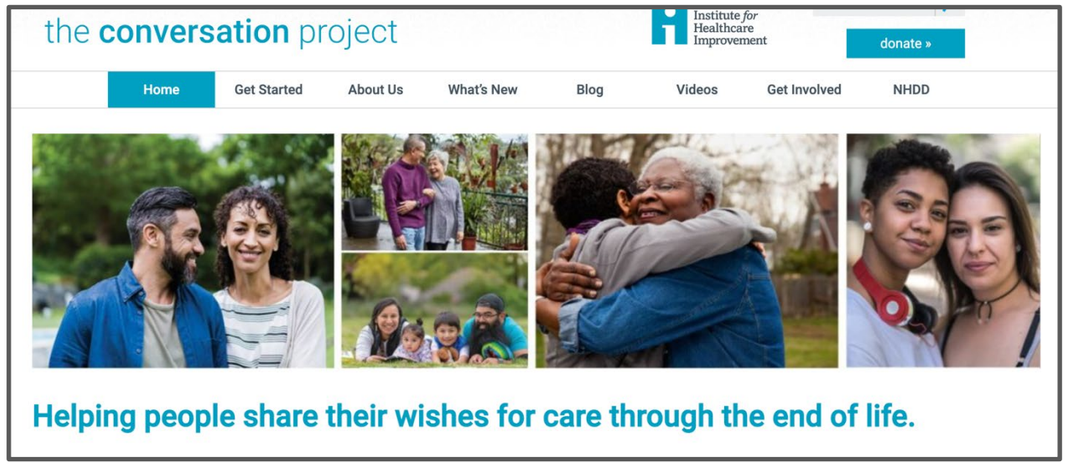
- Assesses end-of-life **values** that we believe to be static and representative of the individual's wishes
- Evaluates end-of-life care **preferences** that may be malleable as caregiving situation AD/ADRD progression
- Has strong psychometric validity and reliability
  - Utility in research & practice
- Applicable for all older adults
- Improves ACP concordance & decision-making self-efficacy
- Reduces relationship strain

OTHER ACP RESOURCES









UTAH GERIATRIC EDUCATION CONSORTIUM

The **goal** of UGEC is to improve long-term health care through education of the workforce

- **Utahgwep.org**
- Education & Trainings
  - Motivational interviewing
  - Goals of care Conversations

UTAH GERIATRIC EDUCATION CONSORTIUM
UGEC

COLLEGE OF NURSING
UNIVERSITY OF UTAH

THANK YOU!

KARA.DASSEL@NURS.UTAH.EDU

OFFICE: 801-646-4667

REFERENCES

3. Sudore RL, Lum HD, You JJ, Hanson LC, Meier DE, Pantilat SZ, Matlock DD, Rietjens JAC, Korfage IJ, Ritchie CS, Kutner JS, Teno JM, Thomas J, McMahan RD, Heyland DK. Defining Advance Care Planning for Adults: A Consensus Definition From a Multidisciplinary Delphi Panel. J Pain Symptom Manage. 2017;53(5):821-32.e1. Epub 2017/01/03. doi: 10.1016/j.jpainsymman.2016.12.331. PubMed PMID: 28062339; PMCID: PMC5728651.

5. van der Steen JT, Ribbe MW, Deliens L, Gutschow G, Onwuteaka-Philipsen BD. Retrospective and prospective data collection compared in the Dutch End Of Life in Dementia (DEOLD) study. Alzheimer disease and associated disorders. 2014;28(1):88-94. doi: 10.1097/WAD.0b013e318293b380. PubMed PMID: 23632265.

6. Institute of Medicine (IOM). Dying in America: Improving quality and honoring individual preferences near the end of life. Washington, D.C.: The National Academies, 2014.

7. Parsons C, McCorry N, Murphy K, Byrne S, O'Sullivan D, O'Mahony D, Passmore P, Patterson S, Hughes C. Assessment of factors that influence physician decision making regarding medication use in patients with dementia at the end of life. Int J Geriatr Psychiatry. 2014;29(3):281-90. doi: 10.1002/gps.4006. PubMed PMID: 23836439.

8. Hertogh C. End-of-life care and medical decision making in patients with dementia. In: Burns A, editor. Standards in Dementia Care-European Dementia Concensus Network (EDCON). New York: Taylor & Francis; 2005. p. 339-54.

9. Menne HL, Whitlatch CJ. Decision-making involvement of individuals with dementia. Gerontologist. 2007;47(6):810-9. PubMed PMID: 18192634.

10. Yadav KN, Gabler NB, Cooney E, Kent S, Kim J, Herbst N, Mante A, Halpern SD, Courtright KR. Approximately One In Three US Adults Completes Any Type Of Advance Directive For End-Of-Life Care. Health Aff (Millwood). 2017;36(7):1244-51. Epub 2017/07/07. doi: 10.1377/hlthaff.2017.0175. PubMed PMID: 28679811.

11. Rao JK, Anderson LA, Lin FC, Laux JP. Completion of advance directives among U.S. consumers. Am J Prev Med. 2014;46(1):65-70. Epub 2013/12/21. doi: 10.1016/j.amepre.2013.09.008. PubMed PMID: 24355673; PMCID: PMC4540332.

12. Harrison KL, Adrion ER, Ritchie CS, Sudore RL, Smith AK. Low Completion and Disparities in Advance Care Planning Activities Among Older Medicare Beneficiaries. JAMA Intern Med. 2016;176(12):1872-5. Epub 2016/11/02. doi: 10.1001/jamainternmed.2016.6751. PubMed PMID: 27802496; PMCID: PMC5304942.

13. Nicholas LH, Bynum JP, Iwashyna TJ, Weir DR, Langa KM. Advance directives and nursing home stays associated with less aggressive end-of-life care for patients with severe dementia. Health Aff (Millwood). 2014;33(4):667-74. Epub 2014/04/09. doi: 10.1377/hlthaff.2013.1258. PubMed PMID: 24711329; PMCID: PMC4159465.

14. Wolff JL, Scerpella D, Cockey K, Hussain N, Funkhouser T, Echavarria D, Aufill J, Guo A, Sloan DH, Dy SM, Smith KM, Investigators SC. SHARING Choices: A Pilot Study to Engage Family in Advance Care Planning of Older Adults With and Without Cognitive Impairment in the Primary Care Context. Am J Hosp Palliat Care. 2020:1049909120978771. Epub 2020/12/17. doi: 10.1177/1049909120978771. PubMed PMID: 33325729.

15. Mitchell SL, Teno JM, Miller SC, Mor V. A national study of the location of death for older persons with dementia. J Am Geriatr Soc. 2005;53(2):299-305. Epub 2005/01/28. doi: 10.1111/j.1532-5415.2005.53118.x. PubMed PMID: 15673356.

REFERENCES

16. Unroe KT, Meier DE. Quality of hospice care for individuals with dementia. J Am Geriatr Soc. 2013;61(7):1212-4. Epub 2013/07/17. doi: 10.1111/jgs.12318. PubMed PMID: 23855849.
17. Moye J, Catlin C, Kwak J, Wood E, Teaster PB. Ethical Concerns and Procedural Pathways for Patients Who are Incapacitated and Alone: Implications from a Qualitative Study for Advancing Ethical Practice. HEC Forum. 2017;29(2):171-89. Epub 2017/01/14. doi: 10.1007/s10730-016-9317-9. PubMed PMID: 28084575; PMCID: PMC5541945.
19. Wendler D, Rid A. Systematic review: the effect on surrogates of making treatment decisions for others. Ann Intern Med. 2011;154(5):336-46. Epub 2011/03/02. doi: 10.7326/0003-4819-154-5-201103010-00008. PubMed PMID: 21357911.
20. Carr D, Khodyakov D. End-of-life health care planning among young-old adults: an assessment of psychosocial influences. J Gerontol B Psychol Sci Soc Sci. 2007;62(2):S135-41. PubMed PMID: 17379683.
24. McMahan RD, Tellez I, Sudore RL. Deconstructing the Complexities of Advance Care Planning Outcomes: What Do We Know and Where Do We Go? A Scoping Review. J Am Geriatr Soc. 2020. Epub 2020/09/07. doi: 10.1111/jgs.16801. PubMed PMID: 32894787.
25. Detering KM, Hancock AD, Reade MC, Silvester W. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. Bmj. 2010;340:c1345. Epub 2010/03/25. doi: 10.1136/bmj.c1345. PubMed PMID: 20332506; PMCID: PMC2844949.
26. Fried TR, Bullock K, Iannone L, O'Leary JR. Understanding advance care planning as a process of health behavior change. J Am Geriatr Soc. 2009;57(9):1547-55. Epub 2009/08/18. doi: 10.1111/j.1532-5415.2009.02396.x. PubMed PMID: 19682120; PMCID: PMC2783892.
27. El-Jawahri A, Podgurski LM, Eichler AF, Plotkin SR, Temel JS, Mitchell SL, Chang Y, Barry MJ, Volandes AE. Use of video to facilitate end-of-life discussions with patients with cancer: a randomized controlled trial. Journal of clinical oncology : official journal of the American Society of Clinical Oncology. 2010;28(2):305-10. Epub 2009/12/02. doi: 10.1200/JCO.2009.24.7502. PubMed PMID: 19949010; PMCID: PMC3040012.
28. Liu D, Yamashita T, Burston B, Keene JR. The Use of Online Health-Management Tools and Health Care Utilization Among Older Americans. Gerontologist. 2020;60(7):1224-32. doi: 10.1093/geront/gnaa068. PubMed PMID: 32525983.
32. Sudore RL, Schillinger D, Katen MT, Shi Y, Boscardin WJ, Osua S, Barnes DE. Engaging Diverse English- and Spanish-Speaking Older Adults in Advance Care Planning: The PREPARE Randomized Clinical Trial. JAMA Intern Med. 2018;178(12):1616-25. Epub 2018/11/02. doi: 10.1001/jamainternmed.2018.4657. PubMed PMID: 30383086; PMCID: PMC6342283.
33. Aslakson RA, Schuster AL, Reardon J, Lynch T, Suarez-Cuervo C, Miller JA, Moldovan R, Johnston F, Anton B, Weiss M, Bridges JF. Promoting perioperative advance care planning: a systematic review of advance care planning decision aids. J Comp Eff Res. 2015;4(6):615-50. Epub 2015/09/09. doi: 10.2217/cer.15.43. PubMed PMID: 26346494.
34. Jain A, Corriveau S, Quinn K, Gardhouse A, Vegas DB, You JJ. Video decision aids to assist with advance care planning: a systematic review and meta-analysis. BMJ Open. 2015;5(6):e007491. Epub 2015/06/26. doi: 10.1136/bmjopen-2014-007491. PubMed PMID: 26109115; PMCID: PMC4480030.

REFERENCES

40. Keeley MP. Family Communication at the End of Life. Behav Sci (Basel). 2017;7(3). Epub 2017/07/15. doi: 10.3390/bs7030045. PubMed PMID: 28708107; PMCID: PMC5618053.

42. Clayton MF, Iacob E, Reblin M, Ellington L. Hospice nurse identification of comfortable and difficult discussion topics: Associations among self-perceived communication effectiveness, nursing stress, life events, and burnout. Patient Educ Couns. 2019;102(10):1793-801. Epub 2019/06/23. doi: 10.1016/j.pec.2019.06.013. PubMed PMID: 31227332; PMCID: PMC6717031.

46. Torke AM, Sachs GA, Helft PR, Montz K, Hui SL, Slaven JE, Callahan CM. Scope and outcomes of surrogate decision making among hospitalized older adults. JAMA Intern Med. 2014;174(3):370-7. Epub 2014/01/22. doi: 10.1001/jamainternmed.2013.13315. PubMed PMID: 24445375; PMCID: PMC3947481.

51. Lum HD, Dukes J, Daddato AE, Juarez-Colunga E, Shanbhag P, Kutner JS, Levy CR, Sudore RL. Effectiveness of Advance Care Planning Group Visits Among Older Adults in Primary Care. J Am Geriatr Soc. 2020;68(10):2382-9. Epub 2020/07/29. doi: 10.1111/jgs.16694. PubMed PMID: 32726475; PMCID: PMC7718376.

52. Atherton KN. Project Five Wishes: promoting advance directives in primary care. J Am Assoc Nurse Pract. 2020;32(10):689-95. Epub 2019/10/01. doi: 10.1097/JXX.0000000000000289. PubMed PMID: 31567780.

53. Towsley GL, Wong B, Mokhtari T, Hull W, Miller SC. Piloting Me and My Wishes-Videos of Nursing Home Residents' Preferences. J Pain Symptom Manage. 2020;59(3):609-17. Epub 2019/11/09. doi: 10.1016/j.jpainsymman.2019.10.030. PubMed PMID: 31711970.

54. Teno JM, Gozalo P, Mitchell SL, Bynum JP, Dosa D, Mor V. Terminal hospitalizations of nursing home residents: does facility increasing the rate of do not resuscitate orders reduce them? J Pain Symptom Manage. 2011;41(6):1040-7. Epub 2011/02/01. doi: 10.1016/j.jpainsymman.2010.07.014. PubMed PMID: 21276698; PMCID: PMC3181123.

55. Rantz MJ, Popejoy L, Vogelsmeier A, Galambos C, Alexander G, Flesner M, Crecelius C, Ge B, Petroski G. Successfully Reducing Hospitalizations of Nursing Home Residents: Results of the Missouri Quality Initiative. Journal of the American Medical Directors Association. 2017;18(11):960-6. Epub 2017/08/02. doi: 10.1016/j.jamda.2017.05.027. PubMed PMID: 28757334.

56. Koppitz A, Bosshard G, Kipfer S, Imhof L. Decision-making in caring for people with dementia at the end of life in nursing homes. Int J Palliat Nurs. 2016;22(2):68-75. doi: 10.12968/ijpn.2016.22.2.68. PubMed PMID: 26926346.

57. Gozalo P, Teno JM, Mitchell SL, Skinner J, Bynum J, Tyler D, Mor V. End-of-life transitions among nursing home residents with cognitive issues. N Engl J Med. 2011;365(13):1212-21. Epub 2011/10/14. doi: 10.1056/NEJMsa1100347. PubMed PMID: 21991894; PMCID: PMC3236369.

58. Miller LM, Whitlatch CJ, Lee CS, Lyons KS. Incongruent perceptions of the care values of hospitalized persons with dementia: a pilot study of patient-family caregiver dyads. Aging Ment Health. 2017:1-8. Epub 2017/01/28. doi: 10.1080/13607863.2017.1280766. PubMed PMID: 28128641; PMCID: PMC5529266.

59. Miller LM, Lee CS, Whitlatch CJ, Lyons KS. Involvement of Hospitalized Persons With Dementia in Everyday Decisions: A Dyadic Study. Gerontologist. 2017. Epub 2017/04/06. doi: 10.1093/geront/gnw265. PubMed PMID: 28379352.

REFERENCES

60. Orsulic-Jeras S, Whitlatch CJ, Szabo SM, Shelton EG, Johnson J. The SHARE program for dementia: Implementation of an early-stage dyadic care-planning intervention. Dementia (London). 2016. Epub 2016/10/16. doi: 10.1177/1471301216673455. PubMed PMID: 27738110.
61. Song MK, Ward SE, Hepburn K, Paul S, Shah RC, Morhardt DJ. SPIRIT advance care planning intervention in early stage dementias: An NIH stage I behavioral intervention development trial. Contemp Clin Trials. 2018;71:55-62. Epub 2018/06/02. doi: 10.1016/j.cct.2018.06.005. PubMed PMID: 29870867; PMCID: PMC6067971.
62. Gaster B, Larson EB, Curtis JR. Advance Directives for Dementia: Meeting a Unique Challenge. JAMA. 2017;318(22):2175-6. doi: 10.1001/jama.2017.16473. PubMed PMID: 29114779.
63. Improvement IfHC. The Conversation Project: Your conversation starter kit. https://theconversationprojectorg/wp-content/uploads/2017/02/ConversationProject-StarterKit-Alzheimers-Englishpdfn.d.
64. van der Smissen D, Overbeek A, van Dulmen S, van Gemert-Pijnen L, van der Heide A, Rietjens JA, Korfage IJ. The Feasibility and Effectiveness of Web-Based Advance Care Planning Programs: Scoping Review. J Med Internet Res. 2020;22(3):e15578. Epub 2020/03/17. doi: 10.2196/15578. PubMed PMID: 32181750; PMCID: PMC7109619.
65. Givens JL, Sudore RL, Marshall GA, Dufour AB, Kopits I, Mitchell SL. Advance Care Planning in Community-Dwelling Patients With Dementia. J Pain Symptom Manage. 2018;55(4):1105-12. Epub 2017/12/14. doi: 10.1016/j.jpainsymman.2017.12.473. PubMed PMID: 29247754; PMCID: PMC5866907.
66. Cattaneo LB, Chapman AR. The process of empowerment: a model for use in research and practice. Am Psychol. 2010;65(7):646-59. doi: 10.1037/a0018854. PubMed PMID: 20873882.
67. Hopp FP. Preferences for surrogate decision makers, informal communication, and advance directives among community-dwelling elders: results from a national study. Gerontologist. 2000;40(4):449-57. PubMed PMID: 10961034.
68. Jung MY, Matthews AK. A Systematic Review of Clinical Interventions Facilitating End-of-Life Communication Between Patients and Family Caregivers. Am J Hosp Palliat Care. 2021;38(2):180-90. Epub 2020/05/29. doi: 10.1177/1049909120929323. PubMed PMID: 32462895.
69. Gitlin LN, Hodgson N. Caregivers as therapeutic agents in dementia care: The evidence-base for interventions supporting their role. In: Gaugler JE, HKane RL, editors. Family caregiving in the new normal. Philadelphia, PA: Elsevier, Inc.; 2015. p. 305-56.

Resilience in Aging Brain Research:

How does the Aging Brain Respond to Stressors?

HEATHER E. WHITSON, MD, MHS

PROFESSOR OF MEDICINE (GERIATRICS), OPHTHALMOLOGY, NEUROLOGY, HEAD & NECK SURGERY AND COMMUNICATION SCIENCES

DIRECTOR, DUKE AGING CENTER

CO-DIRECTOR, DUKE/UNC ALZHEIMER'S DISEASE RESEARCH CENTER

DUKE SCHOOL OF MEDICINE/DURHAM VA GRECC

Disclosures

National Institute on Aging: P30AG028716-11, UH3AG056925, P30-AG064201-02, R01-AG062623-01A1, U13 AG054139, R33-AG057806, P30AG072958-01

Veterans Administration – Durham VA GRECC

AGS Board of Directors

Outline for Today's Talk

1) The importance of **resilience to stressors** in overall human health and aging
2) Frameworks and semantics in resilience research – Friends, not Foes
3) Linking my Concept of Resilience to My Love of the Aging Brain
    -Case Example: Vision loss and the aging brain
    -Case Example: Vascular insults and the aging brain

One Patient's Story

Mrs. M
A widow in Durham, North Carolina, USA

She was diagnosed with colon cancer about 6 weeks before I met her.

Mrs. M's Story

She is 91 years old

-Independent in caring for herself, lives alone

-Teaches Sunday school and sings in the choir, "spry"

-Has 3 daughters, 1 son

"Mama is still large and in charge."

Past medical history:

Vascular: Type II diabetes, hypertension, hyperlipidemia, obesity

Non-vascular: Arthritis, H/o Breast cancer in 1996

Went to see her primary doctor for rectal bleeding ->
Diagnosed with colorectal cancer

A hard decision: Surgery or no surgery?

Mrs. M's Story

Day 1: Blood pressure dropped (78/50); Bleeding from surgical site
-Transfused 2 units of blood and received medicines to keep blood pressure normal

Day 2: **Massive Heart Attack.** Emergency cardiac catheterization shows many blockages. Because of the damage from the heart attack, the heart was failing as a pump.
Unable to immediately open the clots in her heart, in setting of surgical site bleeding.
She was placed on a **ventilator** to support breathing and a "**balloon pump**" was inserted to support her heart.
She remained lucid; giving "thumbs up" sign

“A Week of Hellish Uncertainty”

My team is consulted on Day 3 to assist with decision-making and prognosis in this older and now critically ill patient.

Multiple conversations about family and patient preferences and expectations

Questions I asked myself all week

- How much stress can she take and still regain homeostasis/equilibrium?
- What reduced state will the system be in, when or if it regains stability?
- Is the system showing signs of impending tipping points? Have we reached the point of critical failure (no return)?
- What can we do NOW to best support a system that is in distress and flux?
- Are there tests we could do NOW (or should have done BEFORE) to predict her outcome?

Mrs. M's Course

Day 9: Surgery site bleeding is finally under control enough to undergo cardiac catheterization and removal of clots in heart arteries. Balloon pump removed.

Remains lucid: smiling, nodding appropriately

Slowly weaning from ventilator (a good sign)

Day 11: Ventilator requirements increase; diagnosed with **vent-associated pneumonia**. Self-extubates in early a.m., and had to be re-intubated within hours. First sign of confusion.

Day 12: **Cardiac Arrest, resuscitated**; IV medications to maintain blood pressure have to be restarted, a sign that her heart is failing.

Holiday weekend – family wants to wait to make decisions until full team can participate in conversations.

Mrs. M's Course

Day 14: Kidney function worsens.

Day 16: Patient is confused again (alert, trying to communicate, unable to use alphabet board)

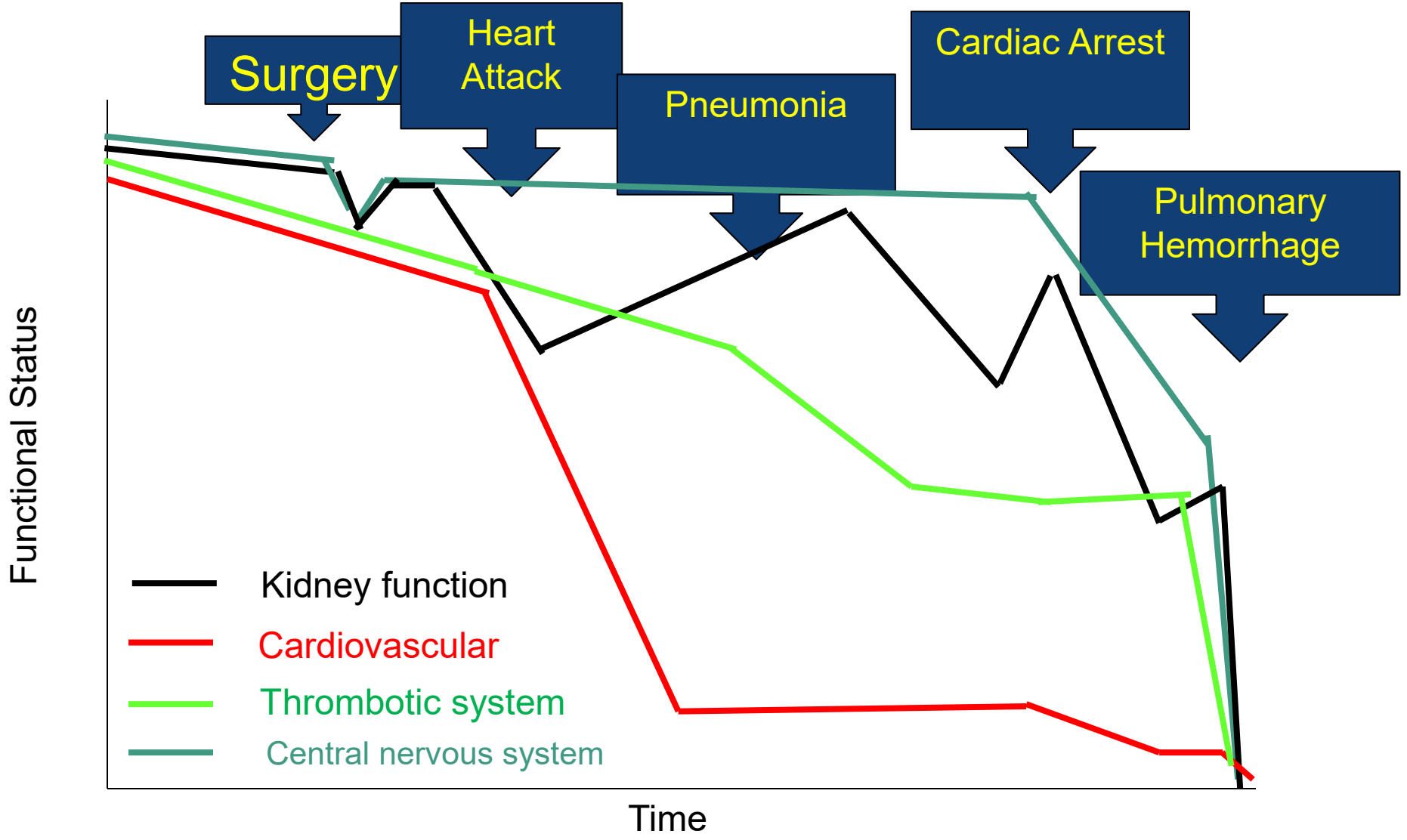
Status Changed: Do Not Attempt Resuscitation

Day 17-20: Some signs of improvement – a little more lucid; kidneys are improving; blood pressure more stable; slow weaning from the ventilator

Mrs. M's Course

Day 21: Sudden pulmonary hemorrhage and cardiac arrest. Mrs. M died with family at her bedside.

In real patients, one stressor often leads to another, and subsystems do not always exhibit the same resilience.



Every person is a complex dynamic system

Interconnected Systems and Sub-systems constantly moving, transitioning, and adapting to changing environments and new stressors

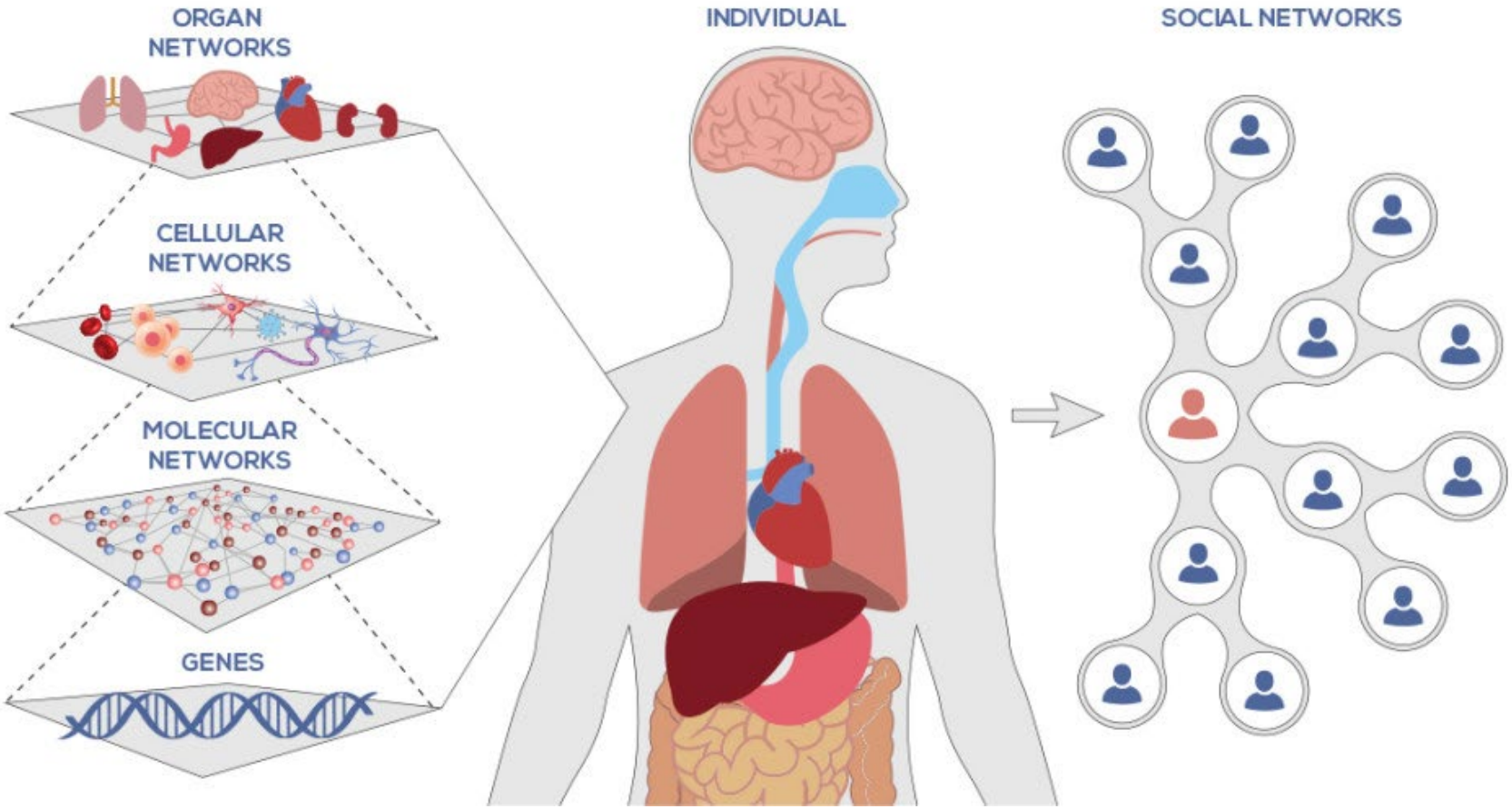
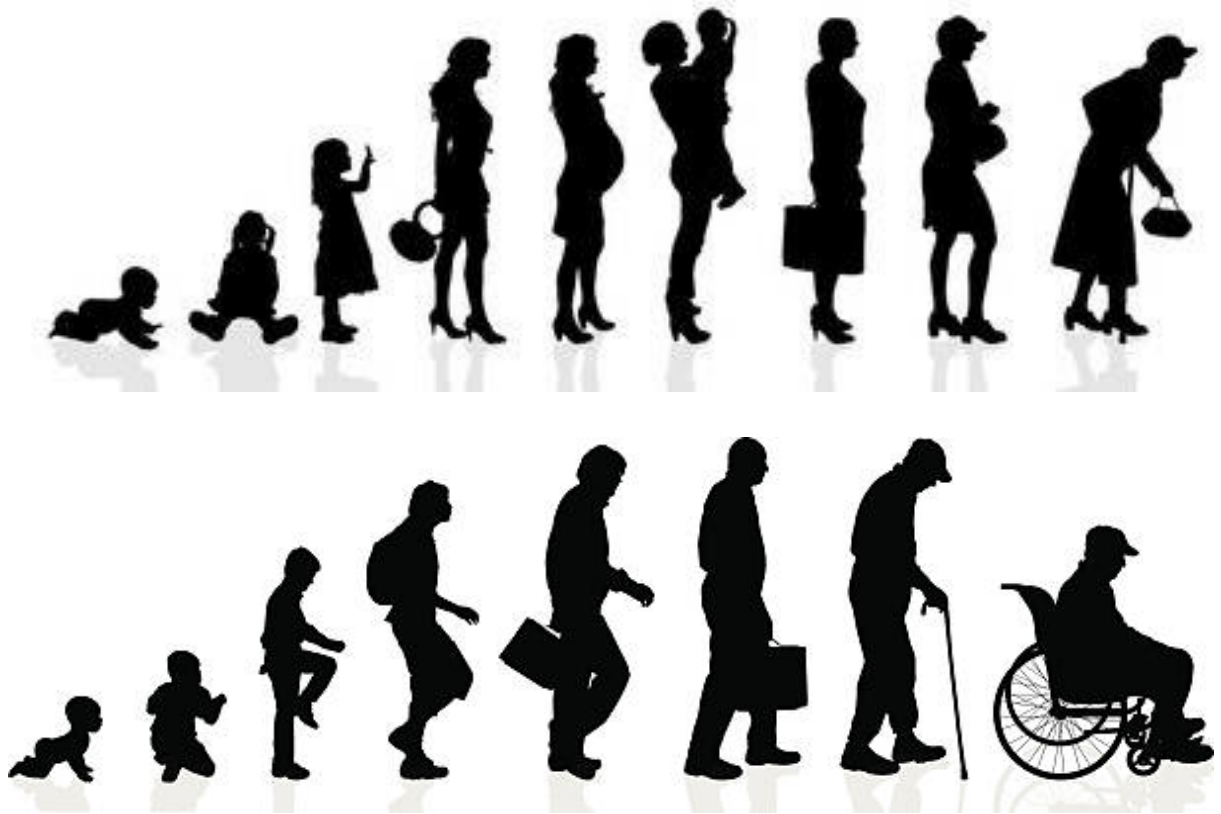


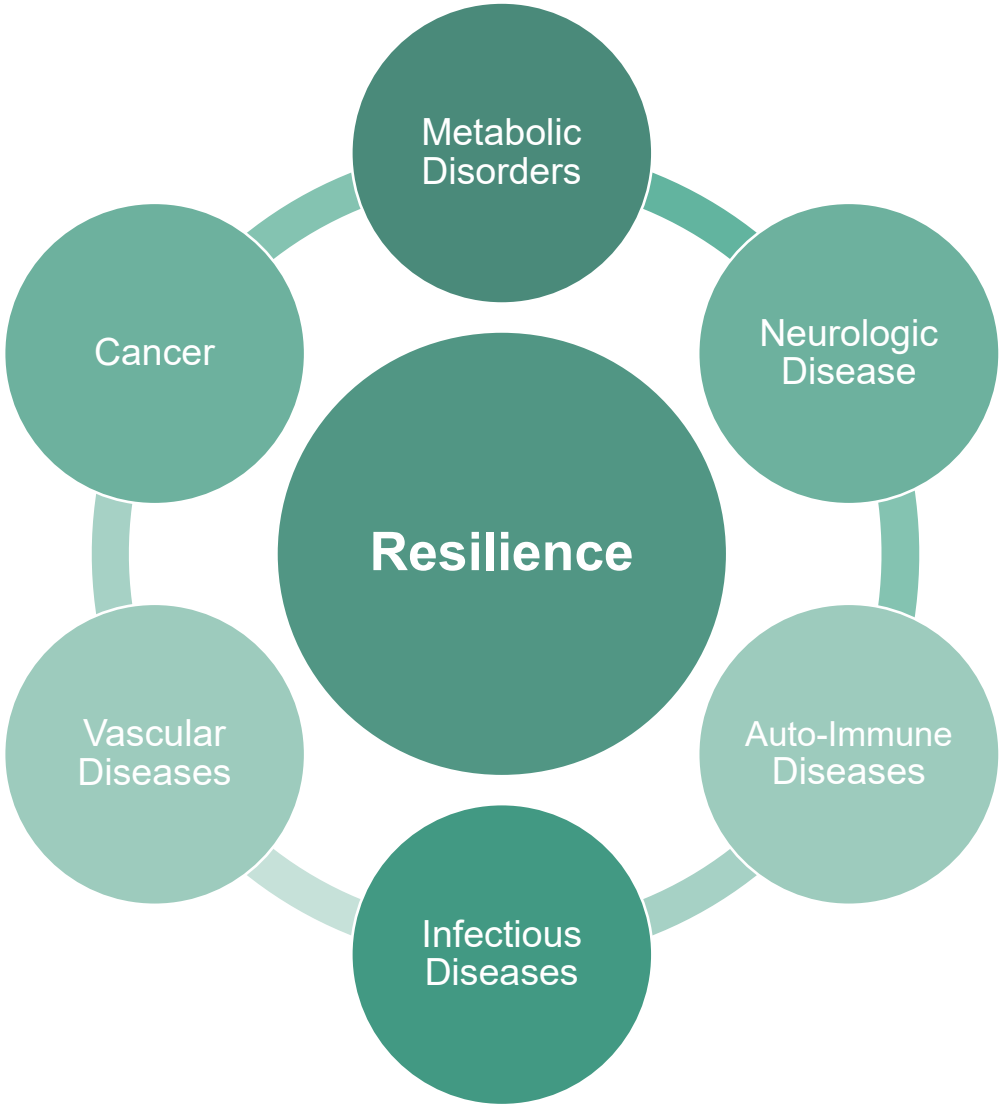
Image by: Institute for Systems Biology, Seattle, WA

With age, our ability to respond briskly and adaptively to perturbation declines.



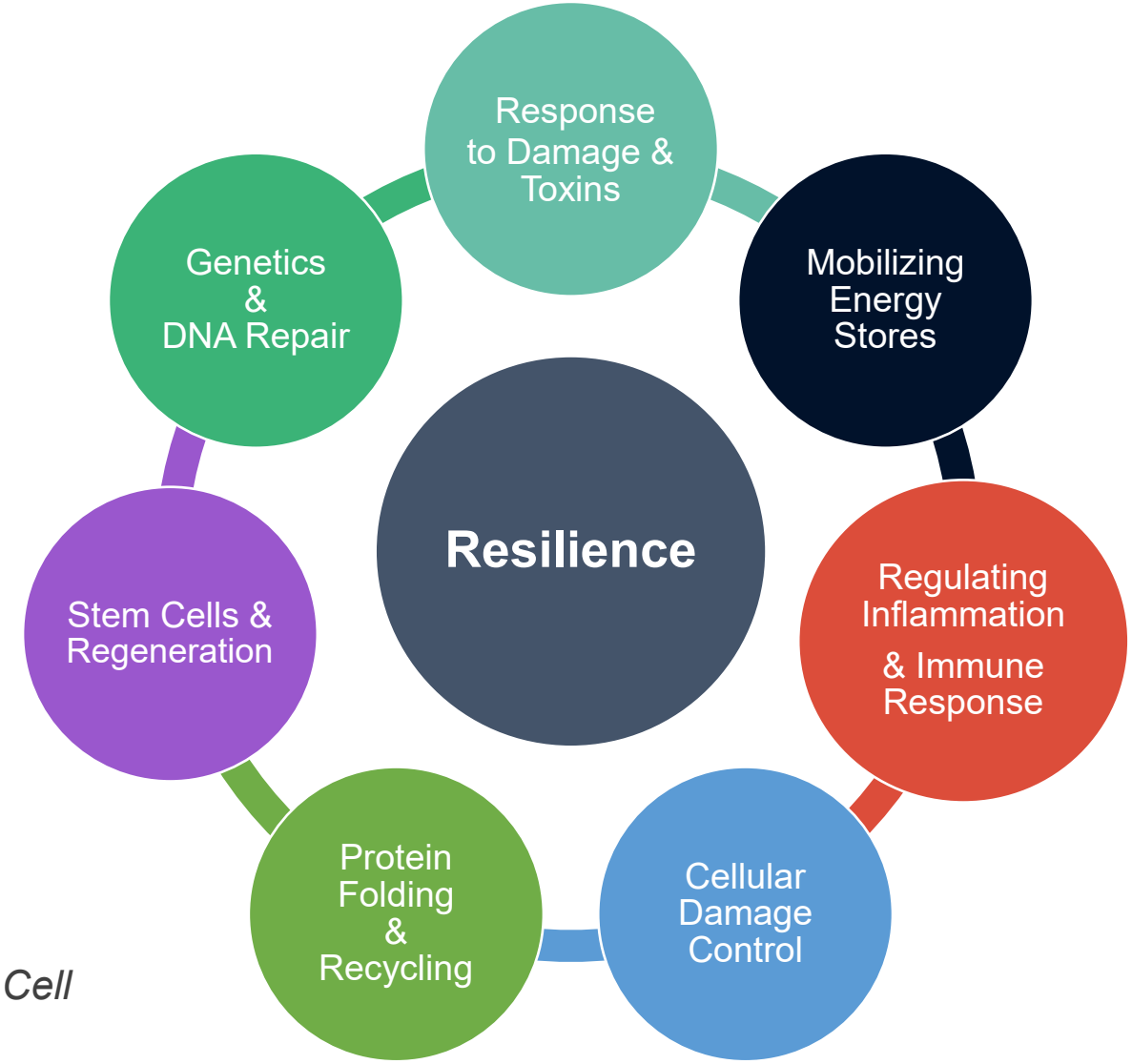
A vicious cycle

Diseases can diminish biologic resilience…



and lower resilience makes us vulnerable to the next disease…

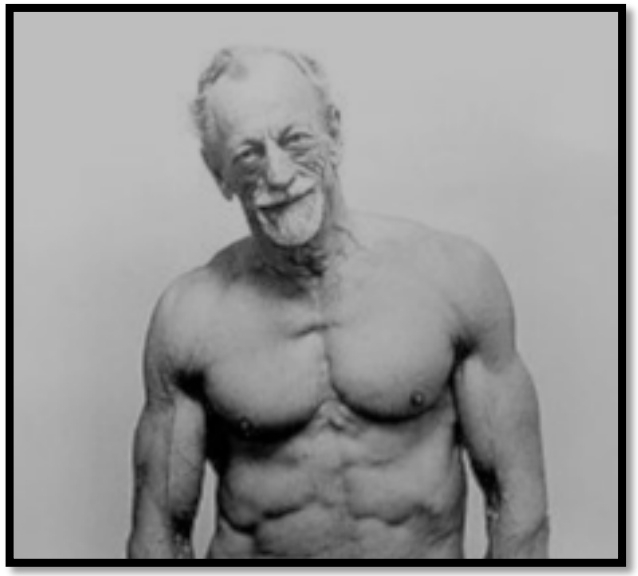
Geroscience: Biological resilience has a molecular basis



…and all of these molecular pathways exhibit decline with age (over time), even in the absence of serious disease.

Adapted from Kennedy et al. *Cell* 159; 2014

But the rate of decline is not the same for everyone. Why?



And sometimes our patients really surprise us…

What influences recovery of function after any health stressor?

Magnitude of the Stressor

Attitude & Mindset

Biological Response to Stress

Support System & Environment

Care & Interventions

Health and Physical Reserve Before the Stressor

Resilience is Everywhere in Medical Research

Trans-NIH Resilience Working Gr

https://ods.od.nih.gov/Research/resilience.aspx#:~:text=Resilience%20Research%20Scientific%20Intere...

National Institutes of Health
Office of Dietary Supplements

Strengthening Knowledge and
Understanding of Dietary Supplements

Health Information | News & Events | Programs & Activities | Grants & Funding | About ODS

Search

Programs and Activities

Share:

Home > Programs & Activities > Trans-NIH Resilience Working Group

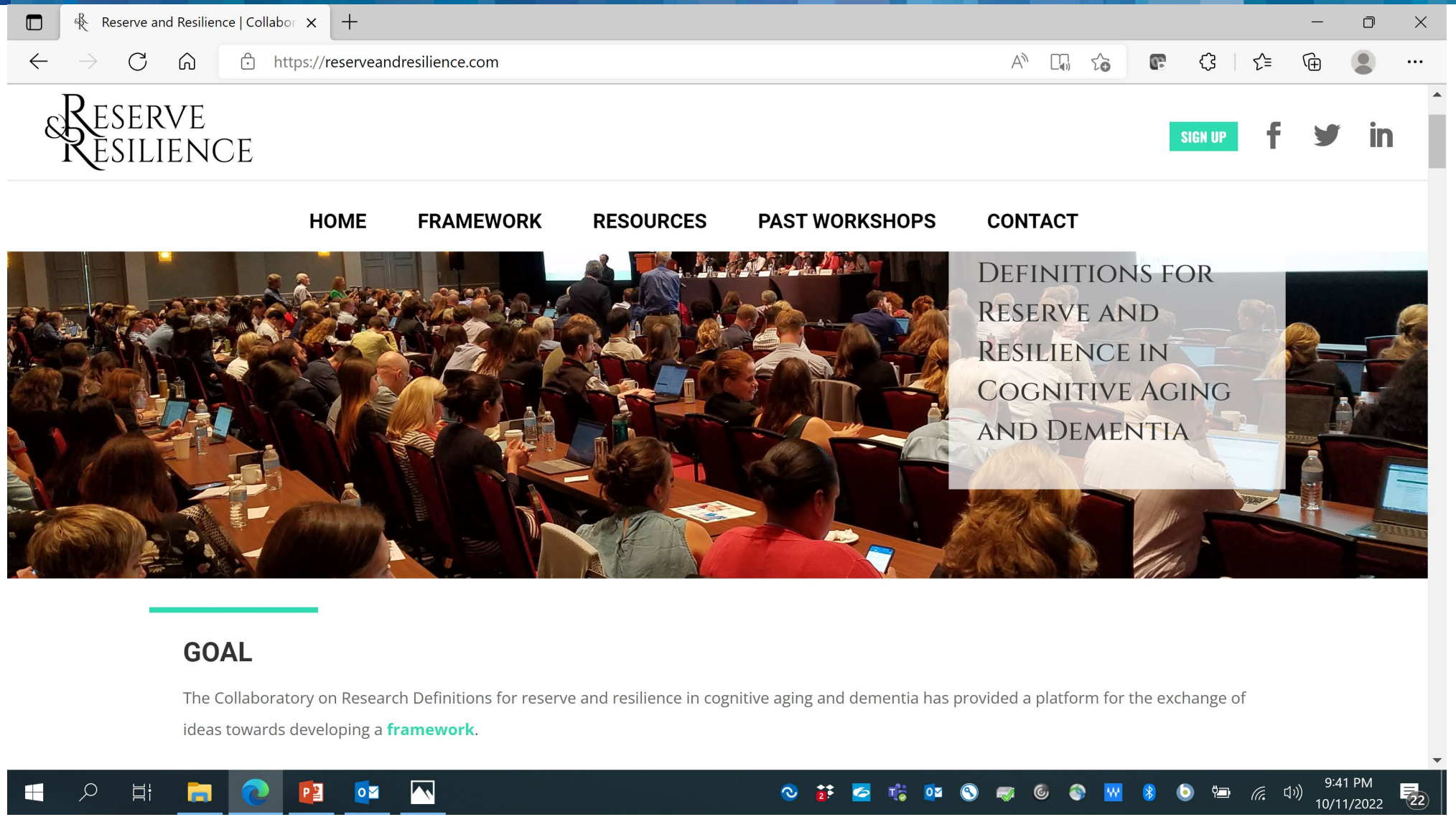
Trans-NIH Resilience Working Group

- Overview
- Defining and Conceptualizing Resilience
- Resilience Research Design Tool
- Resilience Across NIH
  - Resilience Research Scientific Interest Group (SIG)
  - Resilience Research Resources and Helpful Links

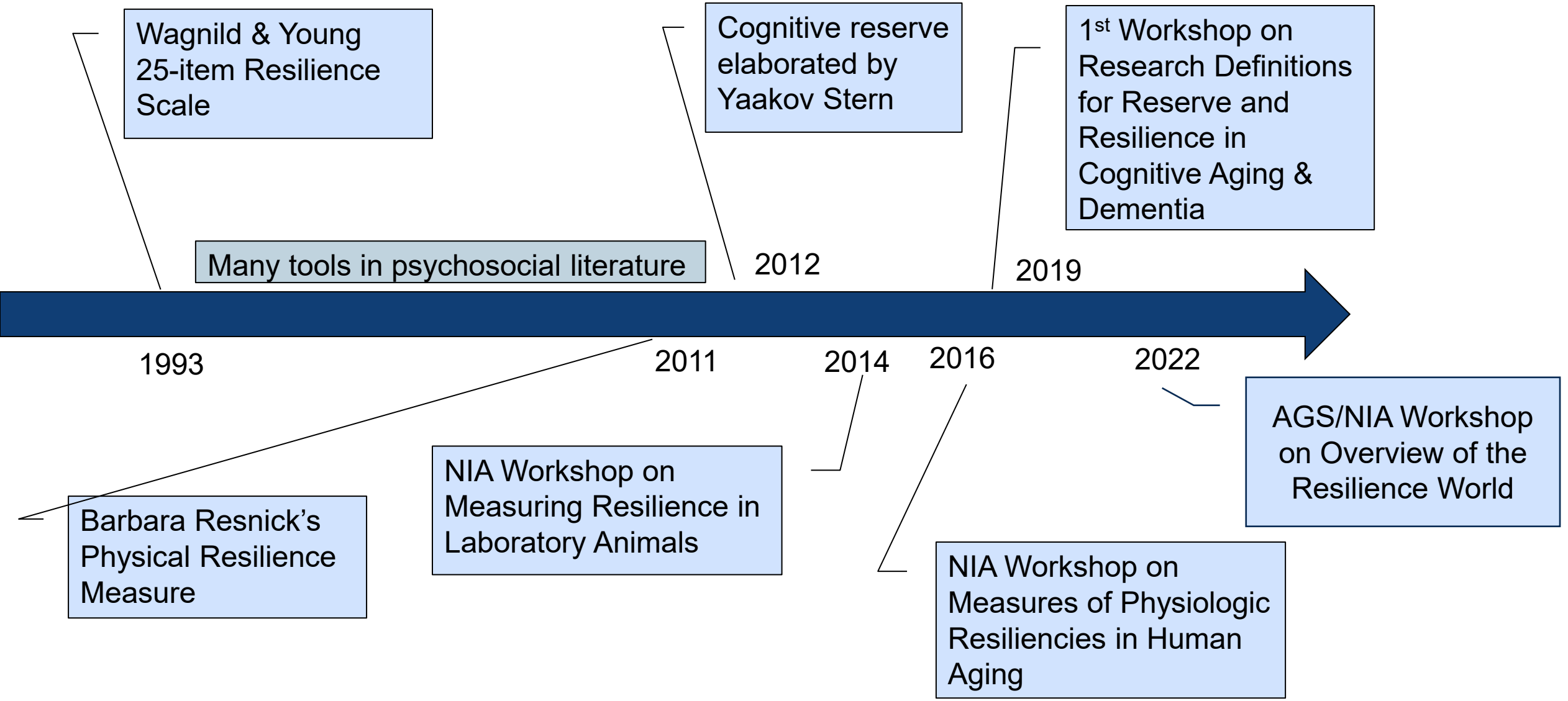
9:44 PM
10/11/2022

Chair: LaVerne L. Brown, Ph.D in Office of Dietary Supplements

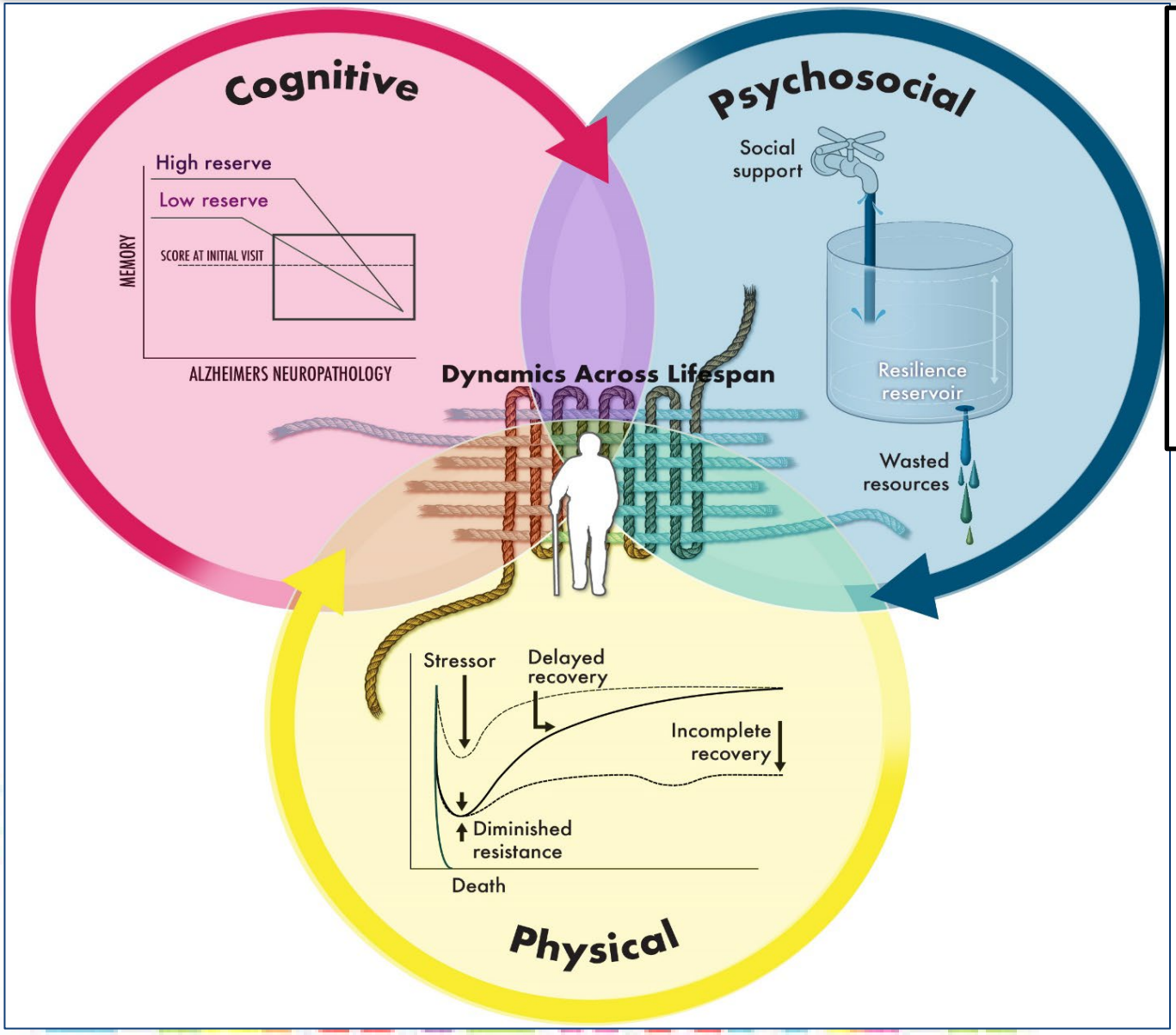
Resilience is Everywhere in Medical Research



A Brief (and surely incomplete) History of Resilience in Aging Research



A cosmopolitan appreciation of “resilience” in health research



DOI: 10.1111/jgs.18388

SPECIAL ARTICLE

Journal of the American Geriatrics Society

An overview of the resilience world: Proceedings of the American Geriatrics Society and National Institute on Aging State of Resilience Science Conference

Peter M. Abadir MD[1] | Karen Bandeen-Roche PhD[1] | Cindy Bergeman PhD[2] | David Bennett MD[3] | Daniel Davis PhD, MRCP[4] | Amy Kind MD, PhD[5] | Nathan LeBrasseur PhD, MS[6] | Yaakov Stern PhD[7] | Ravi Varadhan PhD[1] | Heather E. Whitson MD, MHS[8,9]

1) **Brain Connectivity in Age-related Macular Degeneration**

How does the aging brain respond to the stressor of AMD?

2) **Stressors across the lifespan and risk of Alzheimer's Disease**

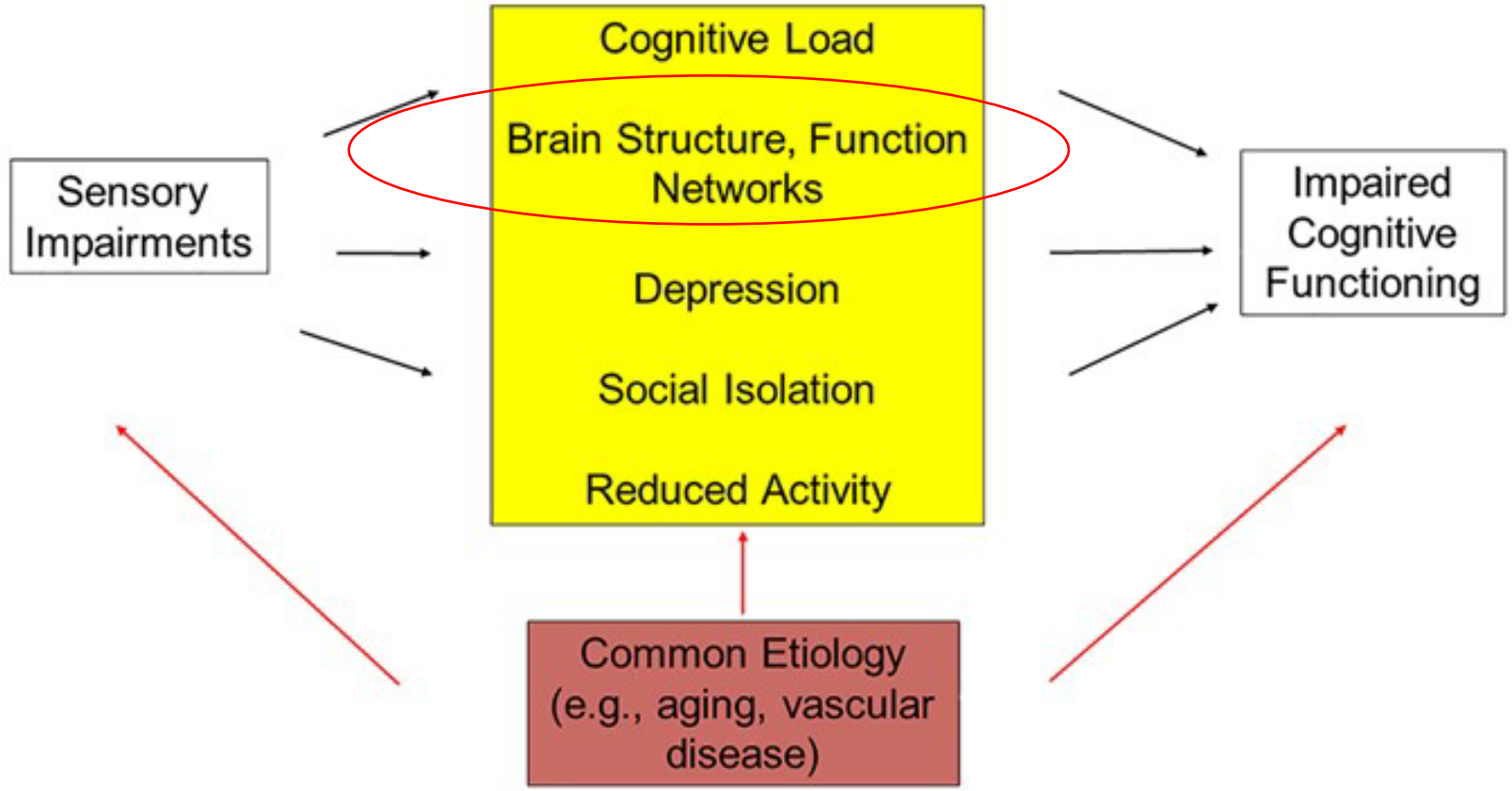
The example of cerebrovascular disease

Example #1:

How does the aging brain respond to the stressor of age-related macular degeneration?

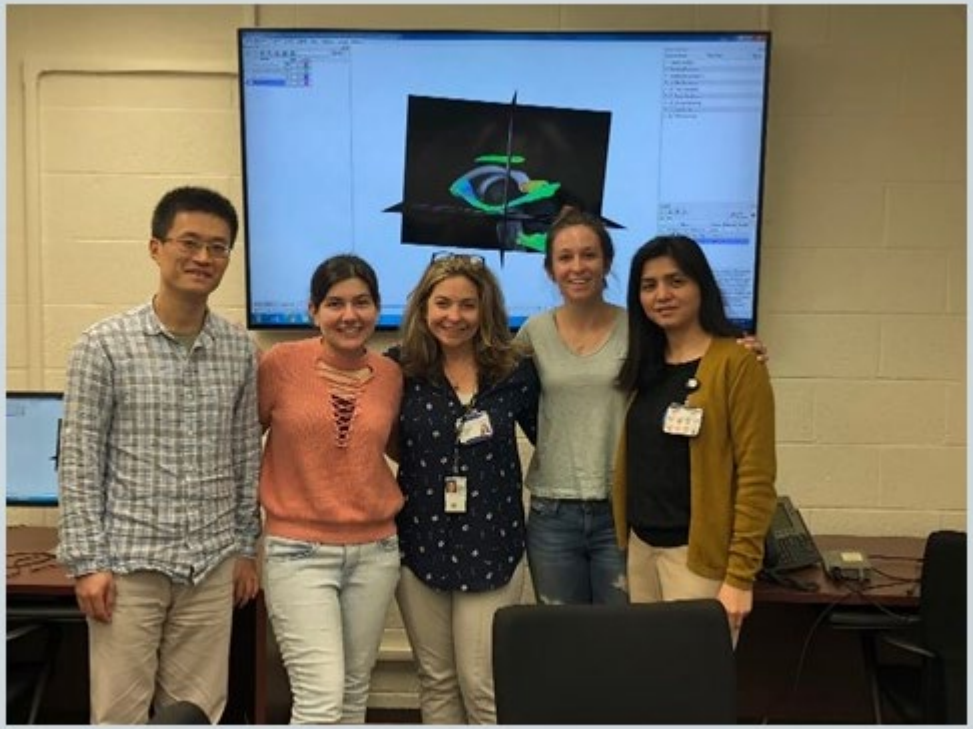
Sensory impairments are linked to dementia, but why?

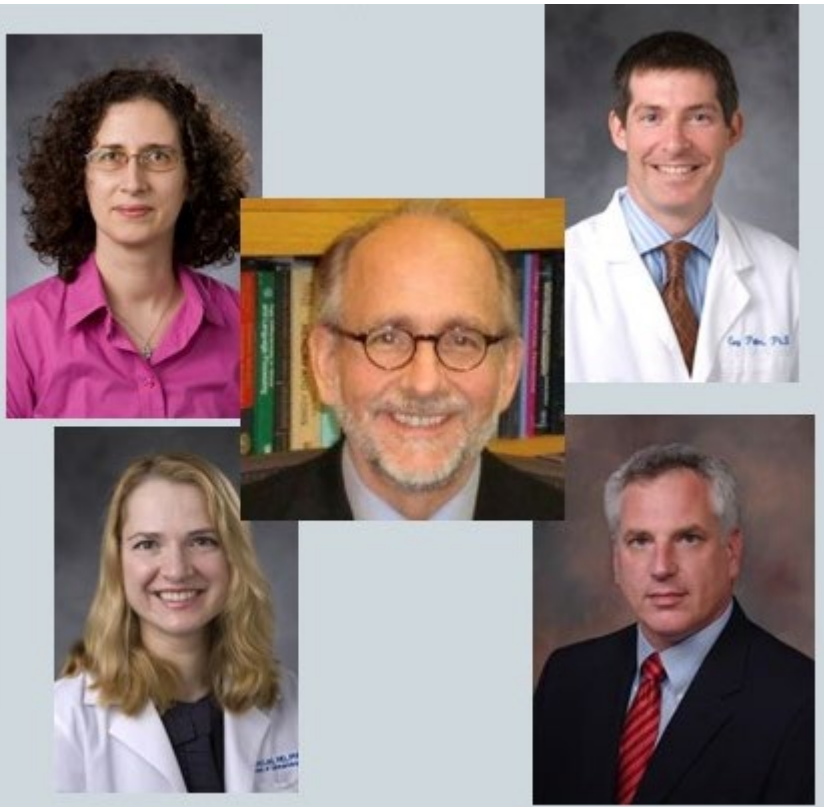
American Geriatrics Society and National Institute on Aging Bench-to-Bedside Conference: Sensory Impairment and Cognitive Decline in Older Adults



Whitson et al., J Am Geriatr Soc 66:2052–2058, 2018

Cognition and Brain MRI in People with and without AMD





81 AMD patients

85 age-matched controls

Mean age 75.5 years

Data on brain changes in the setting of AMD

Data collected at baseline and 2-year follow-up:

Neurocognitive Testing: Verbal fluency, working memory, episodic memory, processing speed, semantic integrity, attention-switching
Health/Life surveys
Audiometry – Pure-tone, Speech-in-Noise, word recognition
Ophthalmol. Data: Dx/Rx, visual acuity, visual function, OCT/photos

Brain MRIs in eligible participants - functional MRI (fMRI) & diffusion tensor imaging (DTI) (n=33 AMD patients, 39 controls)

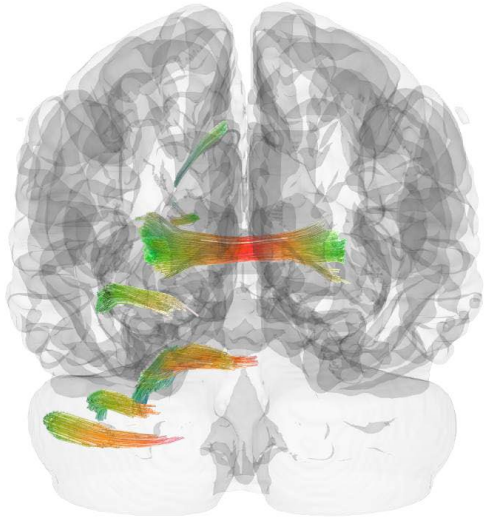
As expected, AMD group under-performed on cognitive tests

	AMD N=81	Controls N=85	P value
Episodic Memory			
Wechsler Logical Memory	24.4	25.1	0.53
Item Recall	5.6	5.6	0.96
Working Memory			
Digit Span Backwards	3.9	3.9	0.98
Verbal Fluency			
Letter Fluency (FAS)	34.3	38.5	0.05
Animal Naming	17.7	19.4	0.05
Semantic Tasks			
Warrington Synonyms	19.0	20.3	0.01
Semantic Decision Speed	1754 ms	1601 ms	<0.01

KEY DISCOVERIES

1) AMD group has worse white matter integrity in certain tracts: **splenium** and several **left-sided ventral and cerebellar** tracts

AMD group has worse White Matter Integrity, compared to Controls, especially in splenium



DSI Studio

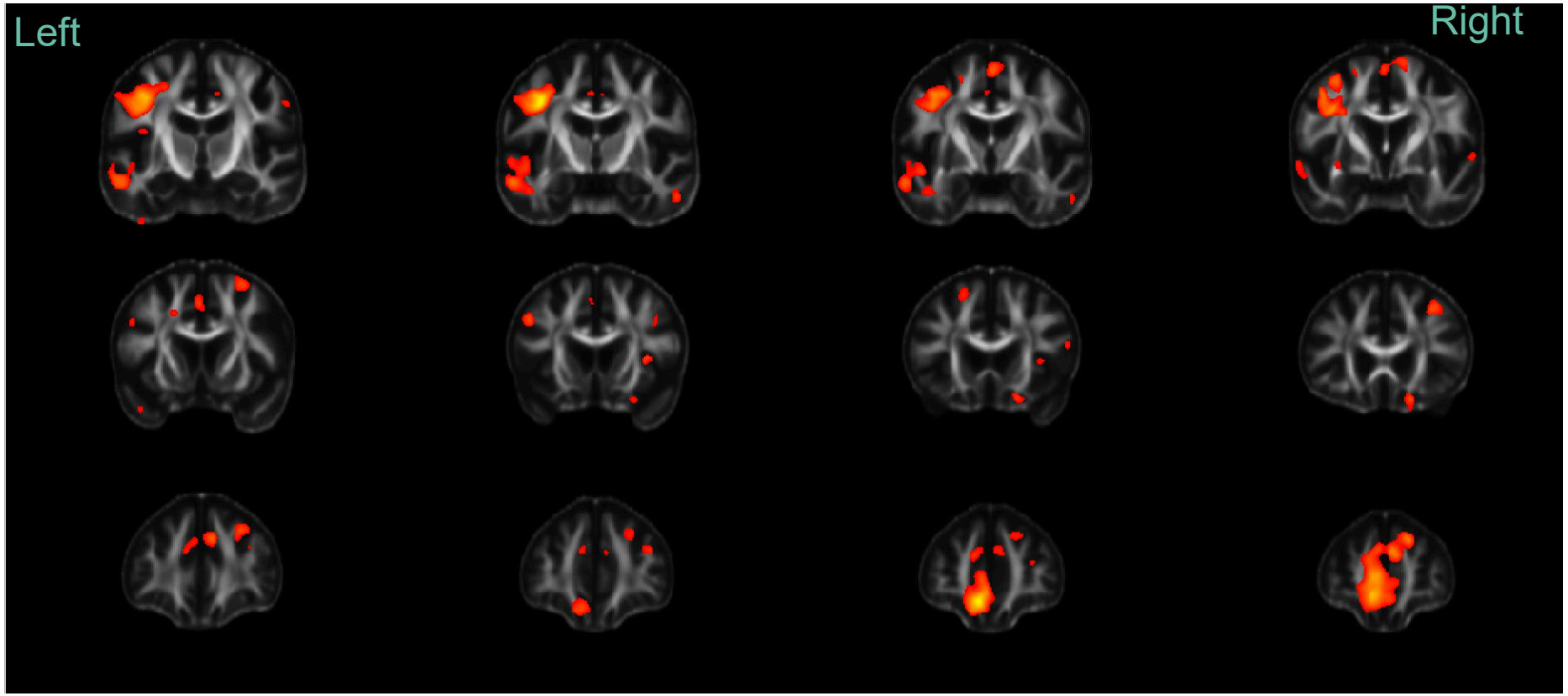
Group Connectometry Analysis
Zhuang et al. *Neuroimage: Clinical* 2021

KEY DISCOVERIES (SO FAR)

2) AMD group has a faster rate of deterioration in white matter tracts, especially on the left side

Comparing Change in White Matter (FA) over 2 Years:

Decrease is greater in AMD group vs. Controls



p = 0.01

[unpublished, in revisions]

KEY DISCOVERIES

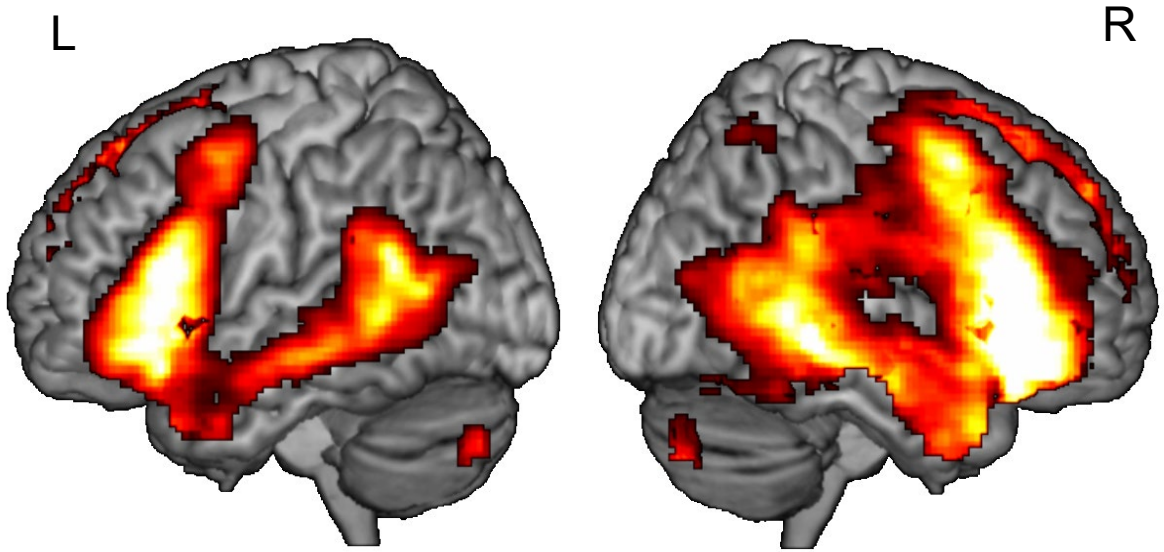
3) We observed a resting-state **functional connectivity pattern** associated with cognitive resilience in AMD

Cognitive resilience defined here as intact/good cognition, despite AMD or despite AMD-associated differences in white matter integrity

Are brain-behavior relationships different in people with AMD-related vision loss vs. age-matched controls?

We were especially interested in how functional connectivity within language-relevant networks might be associated with performance on verbal fluency tasks.

Bilateral Fronto-temporal network

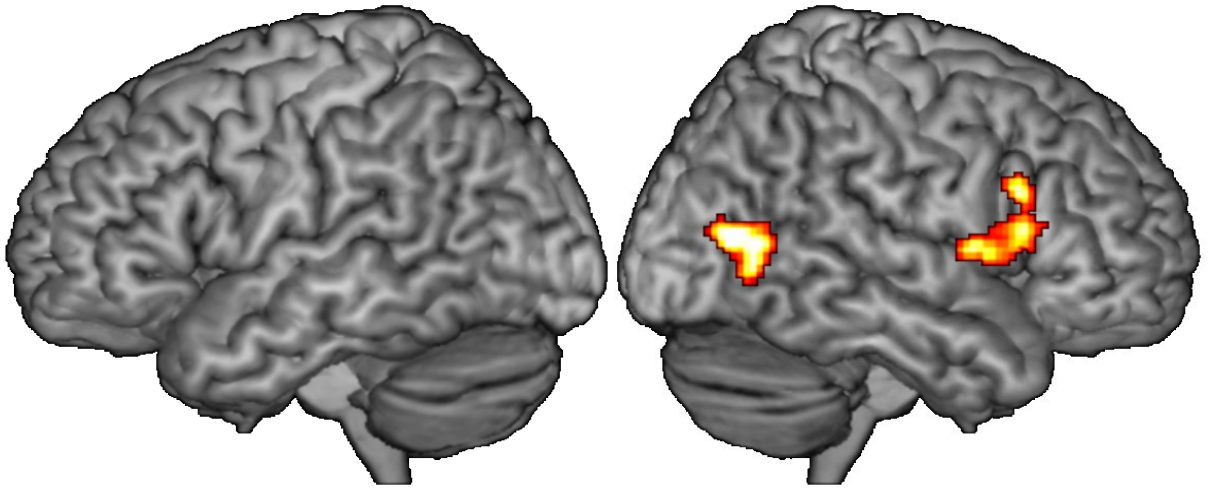


In AMD patients, but not controls, better verbal fluency was associated with **stronger connectivity in right-sided regions of the fronto-temporal network**

AMD patients with better cognitive performance were:

-Better educated

-Exhibited stronger connectivity in right-sided frontotemporal regions



P < 0.05 for AMD vs. control interaction

Zhuang et al. 2018 *Neurobiol Aging* 2018

Summary of these findings

- The group with age-related macular degeneration (AMD) tend to under-perform on several cognitive tasks, particularly related to language/semantics

- AMD patients had worse structural integrity in tracts that are involved in vision and semantic processing.

- Higher connectivity within right-sided regions of a frontotemporal brain network was associated with cognitive resilience in AMD.

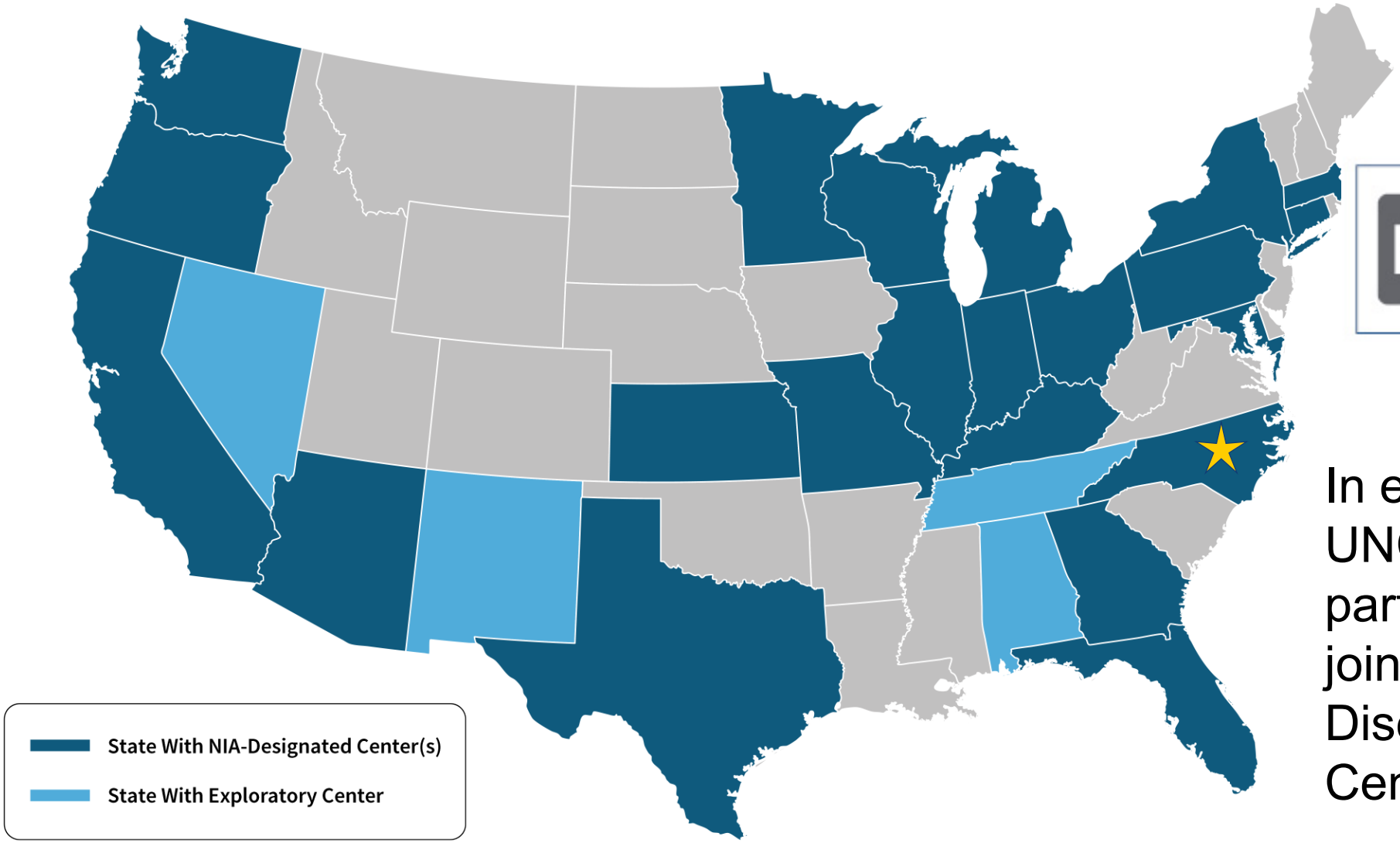
Working Hypothesis: Efficient recruitment of supplemental brain regions may support cognitive performance in the face of structural brain deficits.

Underlying neuropathology (e.g., amyloid/tau) may make it more difficult to cope with vision loss, and *vice versa*

Example #2:

The Duke/UNC Alzheimer's Disease Research Center views Alzheimer's disease as a disease that reflects age-related changes in the brain's resilience to stressors

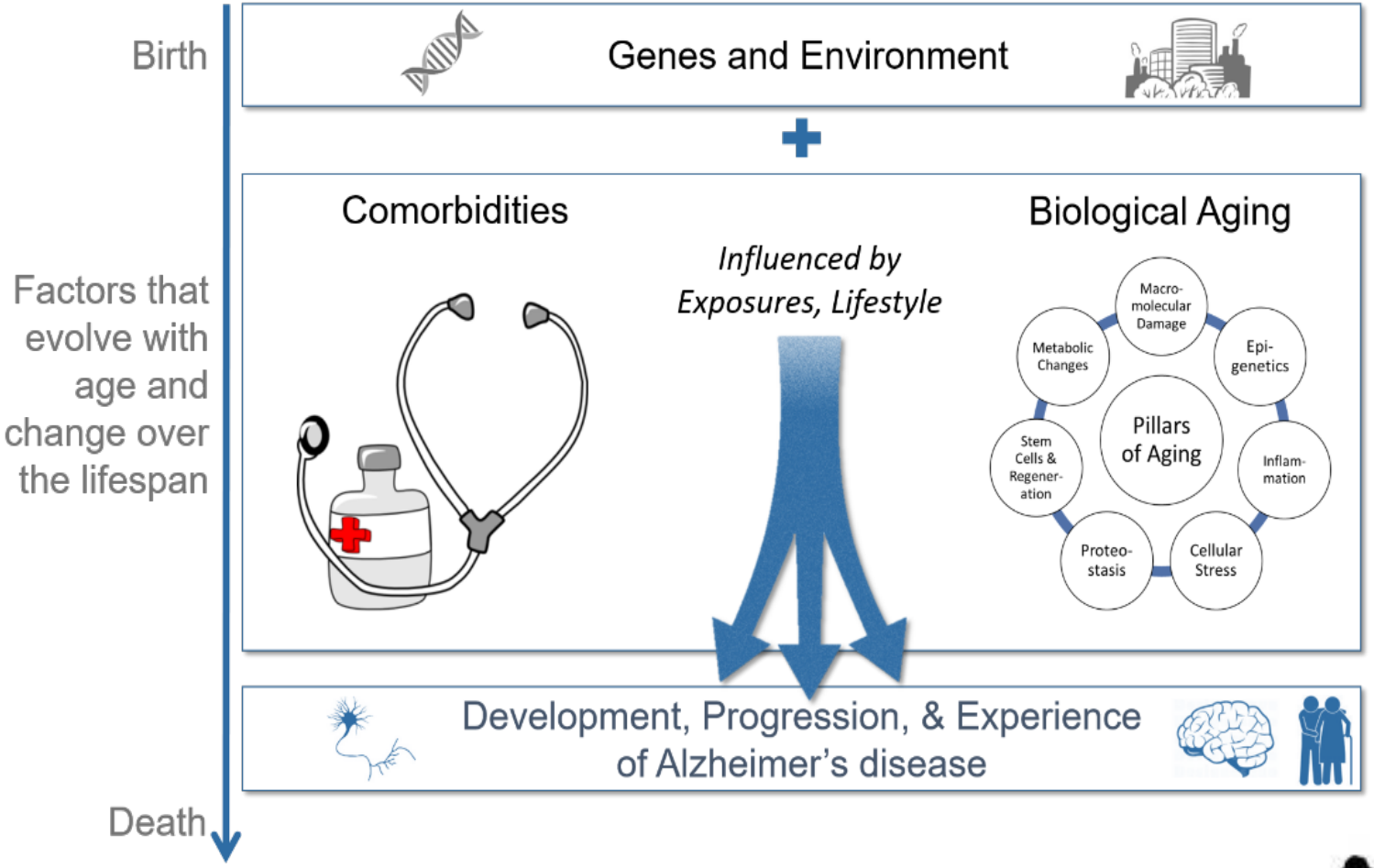
The NIH designates ~30 Centers of Excellence in Alzheimer's Disease & Dementia



NIH National Institute on Aging
Designated
Alzheimer's Disease
Research Center

In early 2020, Duke and UNC established a new partnership to apply jointly for an Alzheimer's Disease Research Center.

Duke/UNC ADRC Theme: Alzheimer's disease develops across the lifespan



Duke Aging Center
Duke University School of Medicine

UNC SCHOOL OF MEDICINE

NIH National Institute on Aging
Designated
Alzheimer's Disease Research Center

Related to prevention of dementia

Lancet Commission Conclusion:
Modifying 12 risk factors across the lifespan can prevent or delay up to 40% of dementia cases.

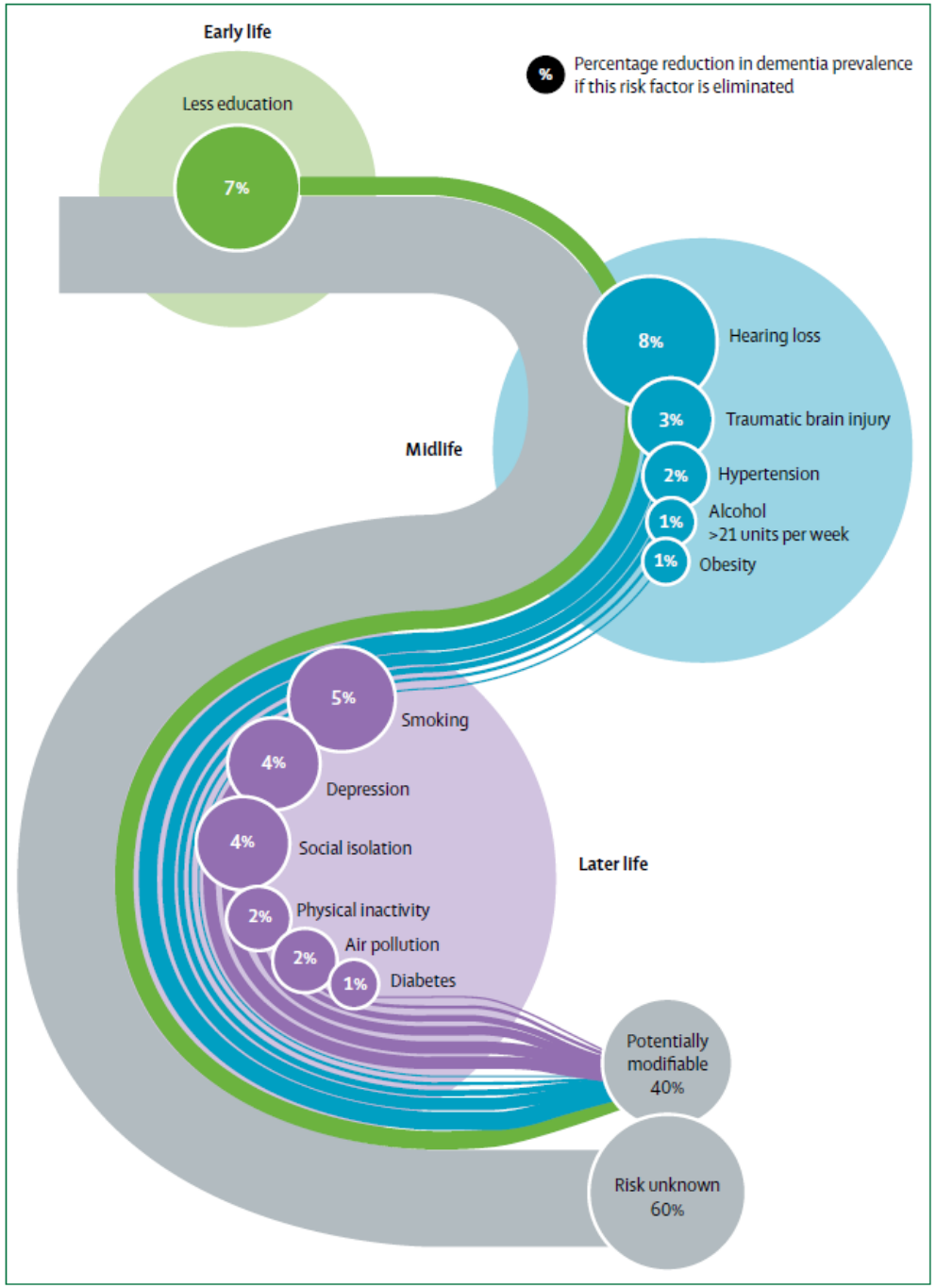


Figure 7: Population attributable fraction of potentially modifiable risk factors for dementia

Livingston et al *Lancet* 2020

The science of dynamic resilience is also key to understanding mechanisms of AD

Interconnected Systems and Sub-systems constantly moving, transitioning, and adapting to changing environments and new stressors

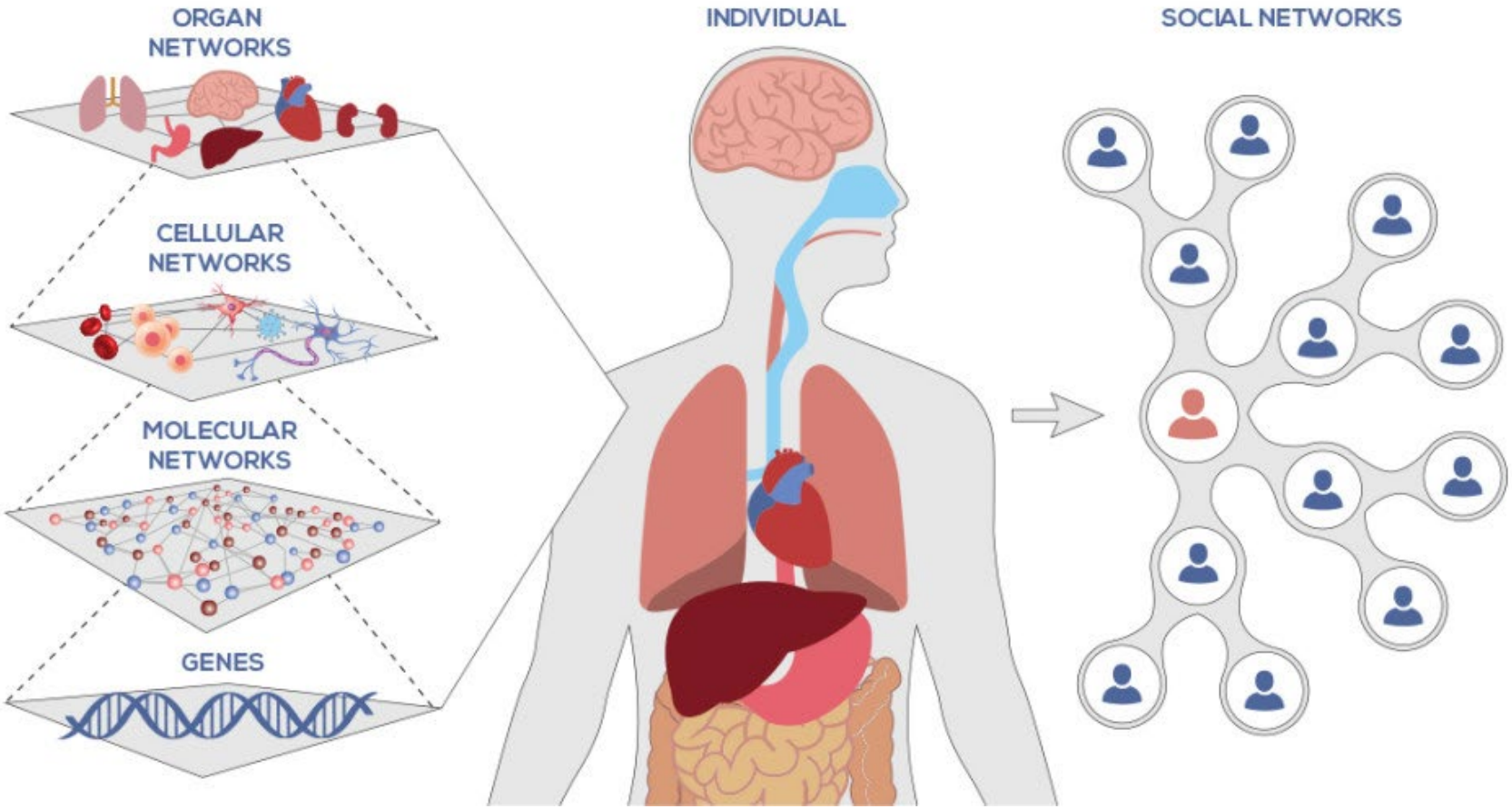


Image by: Institute for Systems Biology, Seattle, WA

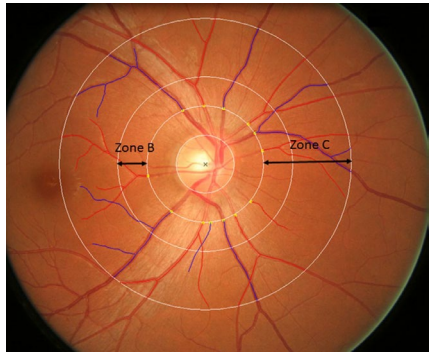
Our goal is to offer unique data to the global fight against AD

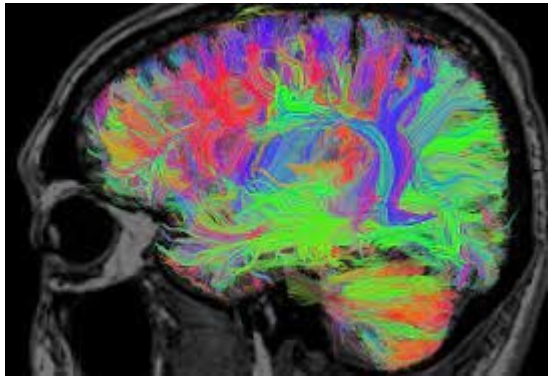
Our participants are younger and more diverse

- Under-represented groups: Black, NA/AI, and people from rural North Carolina
- Biofluids and data across early and mid-life
- Peri-menopausal women

We collect novel data and biomarkers

- Retinal imaging
- Digital biomarkers
- High resolution, advanced MRI techniques
- Sensory and mobility measures





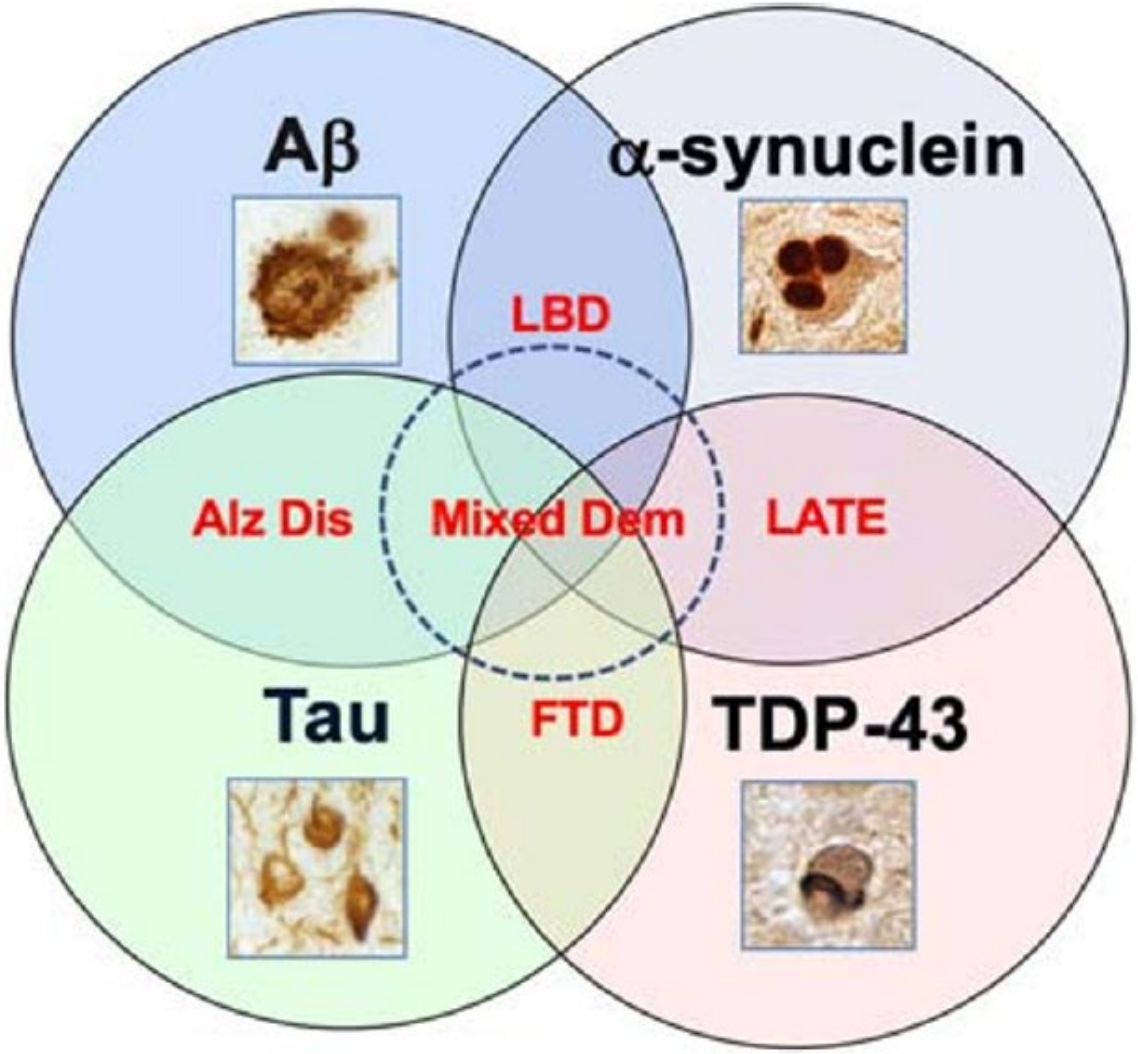
Actively recruiting!

- ~20% UREGs; ~30% from rural zip codes; > 80% donated CSF

Dementia represents a heterogeneous mix of pathologies

Blood Flow

Inflammation



Cellular Metabolism

Brain Injury

Kwon S et al., Neurotherapeutics **17,** 935–954 (2020)

Applying the theme: One example that hits close to home

Targeting changes in the brain's resilience to **vascular insults** across mid- to late-life

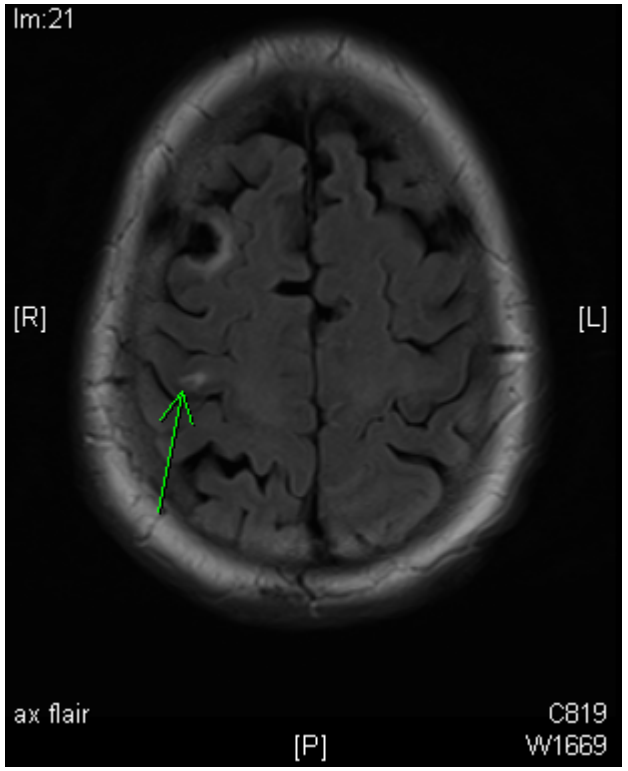
A patient case: 79 year old male for dementia workup

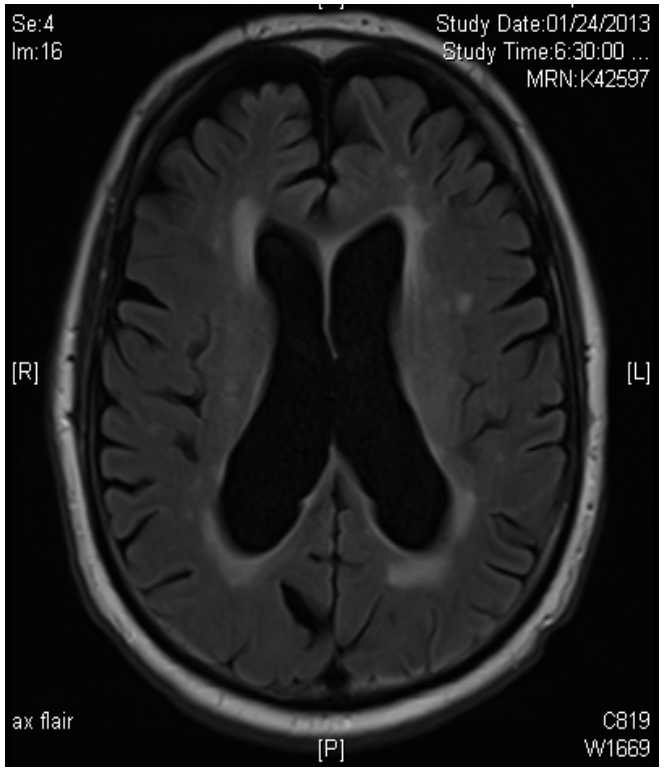
Retired statistics professor
2-3 years of subjective executive dysfunction, memory loss
PMH: HTN, prostate cancer

Montreal Cognitive Assessment (MoCA): 22/30

Over the next 3.5 years:

- Progressive cognitive decline
- Multiple episodes of delirium
- Worsening balance, multiple falls



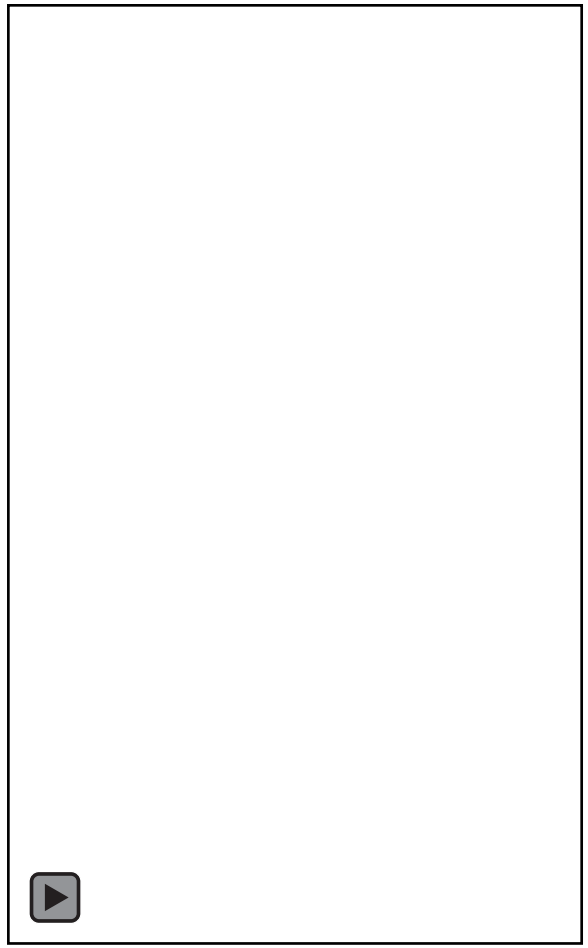


A patient case: 43 year old male presents to ED

"One side of my mouth has been funny since I left the gym this morning."

Symptoms developed ~10 hours earlier

- Left-sided peri-oral numbness
- Hyper-salivation



A patient case: 43 year old male presents to ED

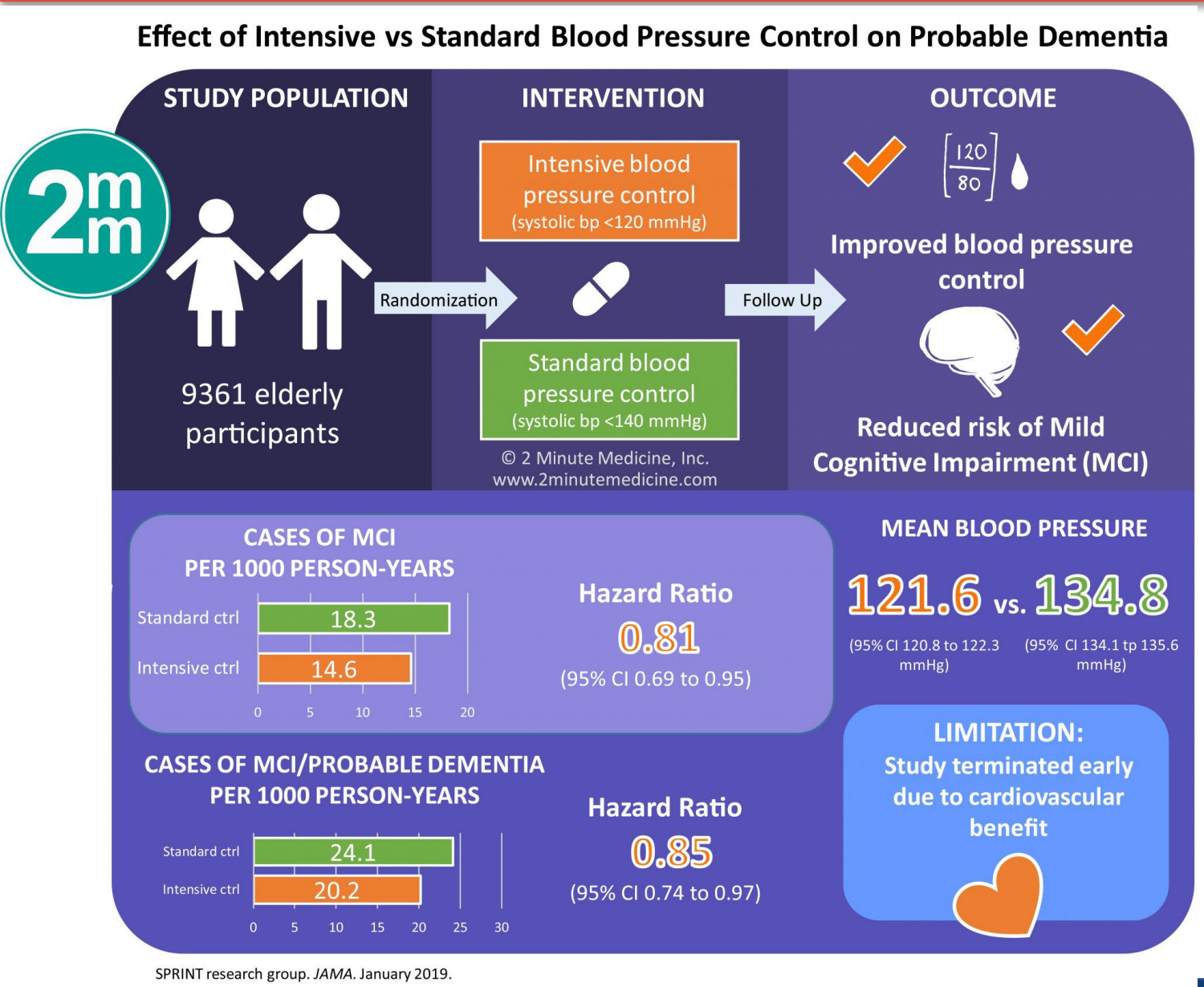
MRI:
Punctate acute or subacute infarct in the right frontal corona radiata.

Diagnosis:
Subcortical ischemic stroke

Post-stroke: Patient is now 49

- Residual symptoms very minor; no functional limitations
- Remains attentive to diet and exercise; gave up cigars
- NEW MEDICATIONS; SBP target <120

Hypertension management: the SPRINT-MIND trial



SPRINT research group. *JAMA*. January 2019.

- 9361 participants age 50+ with SBP > 130 + CVD risk factor
- Randomized to
  - Standard BP control (target SBP <140)
  - Intense BP control (target SBP <120)

Intense BP control over 5 years lowered risk of MCI/dementia

So many questions remain about vascular risk factors & Alzheimer's disease

- Risk of dementia is lower in people who do not have
  - Obesity
  - Type 2 diabetes
  - Hyperlipidemia

- Does treatment of these risk factors in mid- or late-life lower dementia risk or amyloid/tau?
- At the molecular level, how do these risk factors interact with amyloid/tau pathology?
- Or do ischemic injuries simply reduce a brain's ability to maintain cognition when amyloid and tau proteinopathies are present?

An Invitation to Get Involved

Conference #2 will focus on **mechanisms and predictors** of resilience to health stressors.

It will occur in DC area in March 2024

WANT TO BE PART OF IT?
Look for a call late November for applications for Rising Star travel awards to attend!!

DOI: 10.1111/jgs.18388

SPECIAL ARTICLE

Journal of the
American Geriatrics Society

An overview of the resilience world: Proceedings of the American Geriatrics Society and National Institute on Aging State of Resilience Science Conference

Peter M. Abadir MD[1] | Karen Bandeen-Roche PhD[1] | Cindy Bergeman PhD[2] | David Bennett MD[3] | Daniel Davis PhD, MRCP[4] | Amy Kind MD, PhD[5] | Nathan LeBrasseur PhD, MS[6] | Yaakov Stern PhD[7] | Ravi Varadhan PhD[1] | Heather E. Whitson MD, MHS[8,9]

Thank you and Questions

Duke Collaborators:
Cathleen Colon-Emeric, Ken Schmader, Kim Huffman, Bill Kraus, Virginia Kraus, James Bain, Micah McClain, Miles Berger, Marty Woldorff, Daniel Parker, Janet Bettger, Harvey Cohen, Miriam Morey, Carl Pieper, Rick Sloane, Mary Cooter, Jody Feld, Patrick Smith, Katherine Hall
U. Maryland Collaborators:
Jay Magaziner, Denise Orwig, Ann Gruber-Baldini
U. Connecticut Collaborators:
George Kuchel, Jacques Banchereau, Janet McElhaney
Harvard Collaborators:
Lew Lipsitz, Junhong Zhou
NIA Collaborators: Giovanna Zappala, Basil Eldadah, Chhanda Dutta