

CAPRA-NBER Conference Executive Summary
***Financial & Economic Decision-Making, Alzheimer’s Disease,
and Outcomes over the Lifecycle***

Friday October 7, 2022
Cambridge, Massachusetts

Co-Hosted by the Center to Accelerate Population Research in Alzheimer’s (CAPRA) and
the National Bureau of Economic Research (NBER)

Conference Organizers:

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Nicholas W. Papageorge, PhD; Johns Hopkins University
with Kenneth Langa, MD, PhD; University of Michigan
and Jonathan Skinner, PhD, Dartmouth College

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Overview & Goal:

This CAPRA-NBER conference brought together a group of multidisciplinary researchers to develop a network focused on Alzheimer’s Disease & Related Dementia (ADRD). The ultimate goal of the CAPRA-NBER network is to push the ADRD research field forward through novel research collaborations that spark new research efforts. The goal of the initial meeting was to form by sharing across disciplines brief presentations followed by active discussion to delineate where this network may have greatest topical overlap and synergy for advancing the science. The end result was a consensus that the network will regularly convene to advance new research on the financial and economic decision-making consequences and outcomes associated with ADRD and, more generally, ADRD’s impact on lifecycle outcomes. This document contains a summary of 1) the guiding principle for network formation, 2) network next steps and potential future activities, 3) outline of “big scientific questions” identified by attendees, 4) overview of each panel presentation and discussion, 5) attendee contact list, 6) listing of resources available through CAPRA, 7) bibliography of cited publications, and 8) Appendix with presenter slides.

1. Principles Guiding Network Formation

Our principles towards achieving our overarching goal are (1) multidisciplinary views are critical; (2) junior investigators are needed to drive future research agendas; (3) direct connections across disciplines are a huge resource for innovation; and (4) we want to drive complementary rather than competing efforts to advance the field more rapidly. The CAPRA-NBER network will provide a structural foundation to achieve this goal by increasing our collective understanding of ADRD and advance the “big scientific questions” in the ADRD social and economic research space.

2. Potential Future Activities emanating from CAPRA-NBER Network

- Scientific meetings of network mentors inviting mentee/collaborator
- Create mechanism to find collaborators for grants or manuscripts
- Write manuscript delineating research gaps to set guide for future research
- Become a mechanism for developing and/or distributing new data resources
- Develop panel presentations for across disciplinary national meetings

Post-Conference Next Steps for CAPRA-NBER Network

- Share Executive Summary (this document) from Oct. 7 Meeting
- Develop communication channels among members (capra-nber@umich.edu). To use this listserv, send an email to the capra-nber@umich.edu email address and it will reach all CAPRA-NBER members. Alternatively, messages can be sent to the CAPRA email (capra-research@umich.edu) for dissemination.
- Plan for an in-person meeting next year (Fall 2023) at which network members (and an invited mentee if indicated) present works-in-progress. Meeting will be in Ann Arbor, MI.
- Working Papers or Grant Submissions – operationalize ways to foster collaboration between this group in between network meetings.

3. Thematic Summary of Results from Group “Big Scientific Questions”

During the CAPRA-NBER conference, attendees were asked to provide three “big scientific questions” to the moderators (Bynum & Papageorge) that they felt were critical for this network to address. Below are some themes that resulted from the questions received.

1. Early and midlife factors causally related to late life cognitive function & risk of decline
(e.g., *‘What are the causal relationships among IQ, education, occupation, and lifestyle / behaviors and ADRD/cognitive reserve? ‘What do we learn from people who do particularly well later in life?’*)
2. Measurement of Decision-Making capacity and data sources for studying financial outcomes
(e.g., *‘Among individuals with similar levels of brain neuropathology and neurodegeneration; what factors explain differences in cognitive and decision-making performance?’*)
3. Individual decision-making and planning when considering a known probability of dementia in the future
(e.g., *‘If people learn they are likely to become cognitively impaired, do they behave differently thereafter? ‘How do we convey appropriate questions to groups most prepared to answer them?’*)
4. Economic implications of cognitive decline/ADRD on people within family units
(e.g., *‘How do we model decision-making of those who are cognitive impaired and when multiple individuals of (children, spouses, etc.) may take part in those decisions?’*)
5. Impact of social determinants related to race/ethnicity on disparities in care and outcomes in later life (e.g., *‘What do we know about racial inequalities in dementia care access?’*)
6. Understanding linkages or differences between theories of human capital theory and cognitive reserve
(e.g., *‘Is the cognitive reserve model from neuropsychology the same as the ‘cognitive capital’ model economists might develop?’*)
7. Public policy and financing medical, pharmaceutical and long term care for people living with dementia
(e.g., *‘Given the neurological complexities shown by Boyle et al, will an AD-specific drug have a significant population impact?’ ‘What are the effects of disruptions – in support services, living environment, etc.—on health outcomes and/or decision-making among people living with ADRD?’*)

4. CAPRA-NBER Conference Panels

Panel 1: Cognition & Decision Making (How the Brain Works & Ages)

Presenter: Patricia Boyle, PhD

Panelists: Duke Han PhD & Robert Willis, PhD

This panel presented on the intersection of aging and decision-making with emphasis on it being a major public health & economic challenge. Decision-making is important across the lifespan, with older adults facing complex and impactful decisions while also struggling to meet the demands of these decisions with negative consequences (e.g., financial losses associated with elder fraud; bankruptcies). Of importance, to understand cognitive aging and how the brain works, we must also understand that

cognitive aging is messy and more heterogeneous and nuanced than our current model of “no cognitive decline vs. some cognitive impairment vs. dementia”.

Key elements to keep in mind when thinking about cognitive aging and Alzheimer’s are: **(1) Pathology of the brain is ubiquitous:** All older adults when they come to autopsy have some form of dementia, whether or not they exhibited dementia in life. Additionally, there are often comorbidities to take into consideration; **(2) Alzheimer’s Disease and Related Dementia (ADRD) is not one condition:** ADRD is a mixed pathologic condition with approximately 200 combinations. This has implications for intervention and treatment. If a treatment for AD was found, it is still very unlikely a cure would also be found for cognitive decline in the aging population; and **(3) Decision-making declines with advanced age:** There is a disconnect between ability and confidence. Many cognitively intact older adults are also struggling and showing suboptimal decision-making, a harbinger of adverse outcomes with older adults who engage in poor decision-making are more likely to develop AD or MCI.

There is more to be researched to protect us from cognitive aging, with protective factors such as cognitive activity, social engagement & support, and technology use as potential interventions. Conversely, tracking on poor decision-making could lead to earlier detection of ADRD, triggering a plan to action for things financial and health planning.

Key discussion points & questions from this panel included:

- *Complexity of the brain and decision making:* There’s a lot going on in the brain other than amyloid and there’s no “magic bullet” for treatment. The complexity is something researchers will need to struggle with in terms of how the brain affects decision-making and other behaviors at the population level as its not straight forward in its presentation and distribution -
- *Role of the Family:* Older adults don’t want to turn decision-making control over to their family members, even though that may prevent them from getting scammed. Conversely, there’s also the likelihood that some of the family members are the ones exploiting older individuals
- *Leveraging Longitudinal Data Sources* [i.e., [Health & Retirement Study \(HRS\)](#) and cohorts from [Rush Alzheimer’s Disease Center \(RADDC\)](#)]. One panelist referred specifically an article from [Bennett et al \(2018\)](#) looking at the [Religious Orders Study](#) and the [Rush Memory & Aging Project](#) – two longitudinal clinical-pathologic cohort studies of aging & AD. One of the findings was that nuns in their early years were asked to write and they found that nuns who wrote longer more complex sentences were less likely to develop dementia.
- *Nomenclature:* We cannot pick a word to define “these diseases”. We don’t have a cancer of our disease to frame the program and this group should not underestimate the significance to this lack of a standard nomenclature mechanism.
- *Antecedents of Dementia:* Are there ways this group can better identify health or economic factors that trigger early indicators of dementia? For example – one of the earliest warning signs are not mistakes but inefficiencies such as individuals not traveling as frequently as they used to.
- *Decision-Making Models:* Can we take an existing to fit the decision-making of the cognitively impaired person or there a new model that is needed? For reference, Drs. Coile & Chandra wrote a forthcoming paper – [What Can Economics Say about Alzheimer’s](#) – that identifies a set of questions that economists might be well positioned to think about in terms of developing a new model. Our current structures, policies, and laws assume rational decision-making, which is not the case for cognitively impaired older adults.

Panel 2: Markers of Disease & Economic Impact (When the Brain Doesn’t Work)

Presenter: Lauren Nicholas PhD

Panelists: Murat Bilgel PhD, Duke Han PhD, Jason Karlawish MD, and Ken Langa MD PhD

This panel presented on and discussed markers of dementia and disease impacts. Signs and symptoms that have been known about for a long time include erratic bill payments, risk financial decisions, and susceptibility to fraud – but these are often caught late in the disease progression ([Boyle et al 2012](#), [Wildera et al 2011](#), [Spreng et al 2016](#)) and many individuals overstating ability to make decisions after cognitive decline ([Hsu & Willis, 2013](#)). Self-reported difficulties managing money may be predictive of future dementia ([Barnes et al 2014](#)).

There is economic evidence to support the linkages between aging, cognition, and financial decision-making (1) Higher IQ / cognitive functioning associated with better stock allocations and investing behavior ([Browning & Finke 2015](#)); (2) Older investors are worse at stock selection & diversification ([Korniotis & Kumar, 2011](#)); (3) Older adults pay higher interest rates and more fees than younger credit users ([Agarwal et al 2007](#)); and worse Part D choices are made before and after dementia onset vs. never-dementia ([Keane et al 2019](#)). If we could see these symptoms on large-scale datasets (i.e., HRS) and found these indicators earlier, we might be able to intervene to help in different ways. A goal would be to find the signal in the data to do predictive modeling for who is going to develop dementia in the future – combining efforts with these big data sources (HRS, Medicare claims) and the healthcare system to approach this classic public health problem.

The concept of overdiagnosis was raised apropos of the idea that we could identify and diagnose a pathology that will not go on to cause a problem in someone's life is a risk to consider. The cure or diagnosis may be worse than the disease. Combining biomarker data with these other types of data might be a way to decrease false positives. At the individual level, characterizing the natural history is the first step in asking questions – there are lots of signals to be picked up on much earlier than around the period of diagnosis – to which plasma markers & measures may have future significant impact. At the population level, we need to make sure we're taking into consideration cultural social determinants of health (e.g., education) and how those can have protective, or risk factors associated with them.

The whole institutional framework and cognitive decline and financial decision-making often hinges on a well-meaning family member being involved, but it is extremely complicated due to policies such as patient confidentiality.

Key discussion points & questions from this panel included:

- Financial symptoms emerge years prior to diagnosis and can have large impacts on households.
- There are few strategies to recover lost funds – we must prevent loss or optimize transfer time.
- How good can we get at detecting?
- What policy levers can protect or prevent loss?
- Public policy is needed to protect financial security AND financial data – we may need new types of information sharing across institutions and sectors.

Panel 3: Cognitive Impairment and the Family & Caregivers (Impact on or Near Others)

Presenter: Kathleen McGarry PhD

Panelists: Courtney Coile PhD, Ken Langa MD PhD, and Meghan Skira PhD

This presentation focused on the effects of caregivers and potential costs to the family including: (1) out of pocket costs for formal care; (2) labor market effects such as lost wages, lower wage growth / lack of

investment in job, job or career changes to allow more flexibility, lost pension or decreased pension wealth, and difficulty re-entering the labor market; (3) health effects such as physical & emotional burden; and (4) effects on the impaired individual (i.e., do family caregivers provide better or worse care and what is preferred by the recipient?). There are different types of costs for end-of-life spending by cause of death ([Kelley et al 2016](#)) with everything costing more for patients with dementia compounded by the fact that the imputed value of informal care is hard or impossible to provide. Additionally, individuals who provide informal family care are often individuals that have “better” jobs – with more pensions, more vacation, and more resources – therefore it is a higher opportunity cost for those with “more to lose”.

Some challenges on the horizon to family care include (1) declines in fertility meaning there are less kids to take care of their aging parents; (2) changes in disease specific mortality; (3) greater labor force participation for women; (4) migration – children are more likely to live farther away from their parents; (5) increases in divorce and blended families – if you get divorced, you might not have a source to care for you. Conversely, there are some new positive developments in family care that include: (1) paid family leave (in effect in California); (2) technological advances – but also need to consider where the line is wherein a person’s privacy is invaded; (3) medical advances; (4) Home & Community-Based Services (HCBS); and (5) respite care & emotional support.

Key discussion points & questions from this panel included:

Discussed were the concept of – from an economist’s perspective – if private insurance doesn’t work, we should consider social options. Family insurance and social insurance are not perfect substitutes, however, and one might prefer one over other and that we may also need to consider that a diagnosis of Alzheimer’s disease is a risk to the potential caregiver. What is the optimal design of caregiving? Informal caregivers are untrained but there’s a demand for them with many folks interested in being trained. Thinking more downstream, when you engage as a caregiver or have experience with LTC for a person with ADRD, individuals tend to engage in better planning for themselves.

Panel 4: Cognitive Reserve Over the Lifecycle (Development)

Presenter: Kevin Thom PhD

Panelists: Courtney Coile PhD, Matthew Davis PhD MPH, and Robert Willis PhD

There’s a lot of heterogeneity in aging including cognitive responses and cognition after diagnosis or the onset of Alzheimer’s disease. There are three related concepts/terms to discuss ([Cabeza et al 2018](#)).

- *Cognitive Reserve*: A cumulative improvement ...of neural resources that mitigates the effects of neural decline caused by aging or age-related diseases.
- *Cognitive Maintenance*: The preservation of neural resources, which entails ongoing repair & replenishment of the brain in response to damage incurred...owing to ‘wear & tear’.
- *Cognitive Compensation*: Cognition-enhancing recruitment of neural resources in response to relatively high cognitive demand.

The researcher Stern ([2002](#), [2012](#)) makes the distinction between capacity & reserves – very often when you ask people ‘what does cognitive reserve mean?’, you get an answer about brain reserve capacity – the “hardware” of the brain (i.e., synapse count). Cognitive reserve, however, demonstrates the resiliency of the brain and how early it can engage brain networks and cognitive paradigms that are less susceptible to disruption. This is more of a “software” issue. Possible sources of cognitive reserve are: (1) education attainment; (2) work/occupation; and (3) stimulating leisure activities. There’s literature

looking at exposure to institutions such as schools that could improve cognition later in life. There's also literature that focuses on work and staving off decline of cognitive function by being engaged. However more research needing to be done to explore if these relationships are causal. The big question is "what are the effects on changes to a cognitively stimulating activity that will offer a protective effect?".

Key discussion points & questions from this panel included:

Discussed in this panel was the concept that cognitive reserve / resilience pertains to neurological issues other than dementia. There are issues of measurement - we need better data, complex data, and imaging data. We are looking for measurement instruments to break in endogeneity. Could be selection or reverse causation, both of which have high policy implications. Telling someone to go get more education may not help – we need more insight from the biomedical side to help sort out the endogeneity to help with the policy recommendations

There's a strong correlation between how psychologists think about cognitive reserve and how economists think of human capital. At a basic theoretical level, there is a lot of isomorphic potential and a huge gain to be made between bringing together economic theory and clinical perspectives.

Studying cognitive reserve is uniquely well-suited area for this network - neuropsychologists & economists can think about combined impact with sociologists thinking about the life course. There's a question of if cognitive reserve is suitable for thinking about a point in time and the opportunities and insults over a lifetime. For economists, we should be thinking about the parallels of cognitive reserve. The casualty piece is another job economist do a good job thinking about – the causal component has an issue about timing. There may be a very rich research program around cognitive reserve –but more specifically, around decision-making stock and reserve. This split between cognition and decision making is important.

Panel 5: Economic Decisions in the Context of Risk Knowledge (Genetics & Early Diagnosis)

Presenter: Jason Karlawish, MD

Panelists: Ami Ko PhD, Matthew Shapiro PhD, Jon Skinner PhD, and Kevin Thom PhD

There are many ways to measure risk factors without genotyping. Tests can be done in the safety of your own home. You can get biomarker tests and amyloids tests that tell you if your neurons are degenerating. What risks are you measuring, though? Risk of what? It's not the risk of death as there are no studies with Alzheimer's disease that uses death as an endpoint. What do people do with this information? There are lots of decisions in the medical world that are not considered that important but are important in the life of a human. When people learn they have or don't have elevated amyloid levels, they can make rational sense of the information they have and could plan their future. In qualitative data, the word "relief" came up with individuals who had non-elevated levels of amyloid.

Future Planning: Those individuals who learned they had higher amyloid levels communicated to their family members about those issues and started the process of giving power of attorney to others. People begin to think about the problems and making decisions about how they can get taken care of.

In summary, when you tell people that they may lose their mind, people respond by starting to make plans and decisions around how they can get taken care of.

Key discussion points & questions from this panel included:

Discussed after the presentation were the nuances and complexities of risk with an early ADRD diagnosis or genetic test identifying one is at risk:

- *Maintaining Control in the Face of Risk*: In an Institute for Social Research (ISR) study researchers found there was reluctance to turn over control to a trusted familial financial proxy when faced with a potential Alzheimer's disease diagnosis. The individual identified wanting to maintain control in the face of risk.
- *Health Literacy*: That people understand the risks of Alzheimer's after a diagnosis
- *Timing of Diagnosis*: How the timing and duration of disclosure of diagnosis or risk for AD – do people have to be continuously reminded about their risks?
- *Inequality and Access to Personalized Reports*: there may be decision making capital and reserve wherein if you are already in a position to make good choices, you will make even better decisions which could lead to further inequality at the population level.
- *Family Status*: Evaluation of health risks around things like assets are contingent on family status (i.e., married vs. single; children vs. no children). ([Chang & Ko, 2022](#))
- *Future Bad News*: sing a model when looking at risk for Huntington's Disease (HD), [Oster et al](#) used a model that showed how few people got tested for HD because there is no treatment – if you have it you have it. The idea is that this may be better than finding out if you are at risk for AD. The critical difference is there may be things you can do about dementia – but we only have association studies and don't know much about causality.

Panel 6: Challenges & Opportunities in Population Care (Medical Treatment & Long-term Care)

Presenter: Meghan Skira PhD

Panelists: Kathleen McGarry PhD, Edward Norton PhD, Amitabh Chandra PhD, and Kosali Simon PhD

This presentation provided an overview on long-term care payment, skilled nursing facilities, and medical treatment and included potential areas for further research for each.

Payment: Long term care (LTC) typically begins in community-based settings and then transfer into Skilled Nursing Facilities (SNFs). Community-based care is usually in their own home or in a family member's home. *Medicare* only pays if the stay is rehabilitative – including 100 days of care following a hospitalization. Medicare does not pay for non-skilled assistance with ADLs and iADLs. *Medicaid* State plan benefits will cover Home & Community Based Services (HCBS)

Areas for Further Research (Payment):

-Collect current and historical information about state plans and waivers and better understand how these services have changed over time and review what bundles are effective in allowing individuals with ADRD to remain in the community.

-Explore complementary and substitutability among HCBS as well as HCBS + family care. The recent increase in self-direction of HCBS, which allows individuals & families to determine the mix of services & supports. Given the complexity of care for those with ADRD, what are best practices?

Skilled Nursing Facilities: Serve two populations requiring different types of care:

Post-acute care: Short term skilled nursing/rehabilitation after a hospital stay; Medicare is the dominant payer (~ 37% of short-stay residents have ADRD)

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Long-term care: Services for those who can no longer reside independently in the community; Medicaid is the dominant payer (~60% of long-stay residents have ADRD).

14% of SNFs have ADRD special care units (ASCUs)

Quality of care has been a long-standing concern, especially during the Covid-19 pandemic.

- Approaches to improve quality: Regulation, inspection, public reporting, P4P
- Staff turnover is especially problematic.
- Recent evidence on selective admissions and discharges ([Hackmann et al 2021](#); [Gandhi, 2020](#))

Areas for Further Research (SNF):

- Effects of specialization (esp. ASCUs) on patient outcomes and spending
- Peer effects /social interactions
 - ✓ Among residents in shared rooms (exploit variation in discharge incentives)
 - ✓ Among residents in ASCUs; spillovers to non-ASCU residents
- Modeling SNF Choice
 - ✓ What does search processes look like? Characteristics valued by family vs. residents
 - ✓ Challenge: Choice is never observed.
- Addressing turnover
- Impacts of selective admissions/discharges on those with ADRD
- Improving safety/resilience of SNFs against future infection outbreaks

Medical Treatment: Currently 6 FDA approved treatments for ADRD.

-Five treat ADRD symptoms but do not impact the underlying brain changes or disease progression; increase neurotransmitters.

-FDA approved new drug, Aduhelm in June 2021 – reduces amyloid plaques, little evidence of improvement in cognition or functioning.

-Antipsychotics sometimes prescribed (off-label) to treat severe hallucinations, aggression, agitation in those with ADRD.

- ✓ Linked to increased risk of stroke/death among those with ADRD
- ✓ Carry black box warning explaining these risks
- ✓ Prescribing factors into Nursing Home Compare 5-Star Quality rating.

Areas for Further Research (Medical Studies)

- Role of physician detailing in prescribing of FDA-approved treatments for ADRD as well as off-label prescribing of antipsychotics
- Document extent of geographic variation in treatment. Are there important differences in provider-practice styles? Do recent findings in the adolescent mental health context (e.g., [Cuddy & Currie 2020](#)) extend to the ADRD context?

Key discussion points & questions from this panel included:

Reimbursement Incentives: CMS is constantly changing and tweaking incentives, which effects the supply side more than the demand side and decisions by people with dementia. Additionally, home health care is often a key part of keeping people out of the hospital. Two years ago, CMS changed how they reimbursed home healthcare, and we should research the incentives and how that affected people with ADRD.

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International Comparison: There's a big international long term care project looking at variation – one of the big issues internationally is difference in diagnosis. Variation across different countries in regard to how many nursing homes are being used. What fraction of people 50 and older are providing long term care? The US is below the average. We don't have as old a population as these other countries, and we can learn from them going forward.

Health Equity: Need to better understand structural drivers around the disparities in caregivers in the community – disproportionately populations of women of color immigrants.

Validation of Quality Measures: The validation of quality measures in economics has been done. It's easy to make risk adjustment measures however you don't know if it gives you causal effects but what we want to know is if these quality measures are validated. Validation work done on geographic variation is confounded. When mortality effects of being enrolled in Medicare Advantage plans are quantified you see different levels of validation.

Informal Caregiving Matters: Discussed post-presentation was the important role of informal caregiving – the Courtney Van Houtven narrative, "[Standing Up for My Sister](#)" was shared with the group that argued that integrating informal caregivers into the formal health care team benefits the patient, the caregivers, and even health care systems.

5. CAPRA-NBER Network Members

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**Individual was unable to attend CAPRA-NBER conference on October 7, 2022.*

6. Resources from CAPRA

Developed by CAPRA Research Resources Core: [Matthew Davis](#), PhD MPH & [Donovan Maust](#) MD

Data Resources

CAPRA has created a variety of ADRD datasets and analytic tools (such as programming script) that are available on the Data Resources page. Current datasets contain relevant cognitive and dementia-related outcomes for the National Health and Nutrition Examination Survey (NHANES), the National Hospital Ambulatory Care Survey (NHAMCS), the National Health Interview Survey (NHIS), Behavioral Risk Factor Surveillance System (BRFSS), and the Medical Expenditure Panel Survey (MEPS). Additionally, they have developed programming script for use on ResDAC (Medicare claims) data that can be used to identify ADRD. If you have suggestions about future data tools, please contact capra-research@umich.edu.

The Bynum 1-Year Standard Method for Identifying ADRD in Medicare Claims Data

Researchers are now able to download the Bynum-Standard 1-Year Algorithm for identifying Alzheimer's Disease and Related Dementias (ADRD) in Medicare Claims data. Programming script for the algorithm is available in both SAS and Stata and can be used for ADRD identification using both ICD-9 and ICD-10 version codes.

DOI LINK: <https://doi.org/10.3886/E183523V2>

National Hospital Ambulatory Medical Care Survey (NHAMCS):

Six annual data files from 2014 to 2019 using the National Hospital Ambulatory Medical Care Survey (NHAMCS) to identify patient visits to hospital emergency departments where the patient was either diagnosed with Alzheimer's Disease and Related Dementias (ADRD) during the visit using ICD-9-CM and ICD-10-CM codes or was otherwise identified as having ADRD. The datasets also include information on the reason for visit and sociodemographic characteristics.

DOI Link: <https://doi.org/10.3886/E170841V1>

National Health and Nutrition Examination Survey (NHANES) for Dementia Researchers

Three datasets derived from the 2011-12 and 2013-14 NHANES panels (survey years 2011-12, 2013-14, and 2-year appended data file). Datasets include several sociodemographic characteristics merged onto cognition variables. Cognition variables include raw variables and a series of standardized (based on education, race, and age) measures from performance on cognitive tests – both on individual tests and global performance. Visit the repository for this project to find detailed descriptions, data files (in SAS, Stata, and CSV formats), codebooks, and programming scripts (SAS and Stata).

DOI Link: <https://doi.org/10.3886/E151621V1>

National Health Interview Survey (NHIS) for Dementia Researchers

Twelve national annual data files from 2007 to 2018 to identify NHIS respondents with self-reported memory issues. Datasets include several sociodemographic characteristics and cognition variables. In applicable years, datasets include additional merged cognition variables from the Adult Functioning and Disability supplement. NHIS utilizes complex survey design measures to make national annual estimates. Visit the repository for this project to find detailed descriptions, data files (in SAS, Stata, and CSV formats), codebooks, and programming scripts (Stata).

DOI Link: <https://doi.org/10.3886/E154401V1>

[Behavioral Risk Factor Surveillance System \(BRFSS\) for Dementia Researchers](#)

Six annual data files from 2013 to 2018 using the full-year BRFSS data on cognitive functioning. Datasets use a series of self-reported measures on cognitive limitations to identify respondents with potential cognitive issues. Datasets also include BRFSS module on caregiving to identify individuals reporting offering care to individuals living with dementia. Data merged with sociodemographic characteristics and state FIPS codes (to make state level estimates). Visit the repository for this project to find lists of included states for each year and module, detailed descriptions of the datasets, data files (in SAS, Stata, and CSV formats), codebooks, and programming scripts (Stata).

DOI Link: <https://doi.org/10.3886/E154421V1>

[Medical Expenditure Panel Survey \(MEPS\) for Dementia Researchers](#)

Five annual data files using data from 2015 to 2019 to identify MEPS respondents with a diagnosis of dementia using truncated ICD (9 and 10) codes in the medical conditions files. Diagnosis data merged on annual healthcare spending estimates, sociodemographic characteristics, and other health utilization measures. Complex survey design allows users to make national estimates of dementia diagnosis. Visit the repository for this project to find detailed descriptions, data files (in SAS, Stata, and CSV formats), codebooks, and programming scripts (SAS and Stata).

DOI Link: <https://doi.org/10.3886/E154381V1>

[Minding Memory Podcast](#)



The focus of this podcast is to discuss topics related to dementia research. This is an all-hands-on-deck moment for dementia research, and we have topics for both those new to the space as well as old pros. We start with some basics, like: What exactly is dementia? What are the different types of dementia? What is the TICS, if not a swarm of blood-sucking insects? But we also invite researchers on to discuss their interesting work to give you a glimpse at the questions, data, and methods moving the field forward.

[CAPRA Data Briefs](#)

CAPRA has recently started a data briefs series to highlight the use of CAPRA ADRD-relevant datasets. These 2-page reports are descriptive analyses used to demonstrate the types of measures that can be found in CAPRA-constructed datasets as well as provide insights into the ADRD population.

[CAPRA Seminar Series](#)

The purpose of the seminar series is to highlight and discuss relevant data resources and analytic techniques for conducting dementia research. Each seminar is about 20 minutes long.

7. Bibliography of Cited Publications

Agarwal, S., Driscoll, J.C., Gabaix, X. and Laibson, D.,. The age of reason: Financial decisions over the lifecycle. National Bureau of Economic Research. 2007 [doi. 10.3386/w13191](https://doi.org/10.3386/w13191)

Atalay K, Barrett GF, Staneva A. The effect of retirement on elderly cognitive functioning. *J Health Econ.* 2019;66:37-53. doi:10.1016/j.jhealeco.2019.04.006 [PMID 31108435](https://pubmed.ncbi.nlm.nih.gov/31108435/)

Banks J, Mazzonna F. The Effect of Education on Old Age Cognitive Abilities: Evidence from a Regression Discontinuity Design. *Econ J (London)*. 2012;122(560):418-448. doi:10.1111/j.1468-0297.2012.02499.x [PMID 22611283](https://pubmed.ncbi.nlm.nih.gov/22611283/)

Barnes DE, Beiser AS, Lee A, et al. Development and validation of a brief dementia screening indicator for primary care. *Alzheimers Dement.* 2014;10(6):656-665.e1. doi:10.1016/j.jalz.2013.11.006 [PMID 24491321](https://pubmed.ncbi.nlm.nih.gov/24491321/)

Bennett DA, Buchman AS, Boyle PA, Barnes LL, Wilson RS, Schneider JA. Religious Orders Study and Rush Memory and Aging Project. *J Alzheimers Dis.* 2018;64(s1):S161-S189. doi:10.3233/JAD-179939 [PMID: 29865057](https://pubmed.ncbi.nlm.nih.gov/29865057/)

Bonsang E, Adam S, Perelman S. Does retirement affect cognitive functioning?. *J Health Econ.* 2012;31(3):490-501. doi:10.1016/j.jhealeco.2012.03.005 [PMID 22538324](https://pubmed.ncbi.nlm.nih.gov/22538324/)

Boyle PA, Yu L, Buchman AS, Laibson DI, Bennett DA. Cognitive function is associated with risk aversion in community-based older persons. *BMC Geriatr.* 2011;11:53. Published 2011 Sep 11. doi:10.1186/1471-2318-11-53 [PMID 21906402](https://pubmed.ncbi.nlm.nih.gov/21906402/)

Boyle PA, Yu L, Wilson RS, Leurgans SE, Schneider JA, Bennett DA. Person-specific contribution of neuropathologies to cognitive loss in old age. *Ann Neurol.* 2018;83(1):74-83. doi:10.1002/ana.25123 [PMID 29244218](https://pubmed.ncbi.nlm.nih.gov/29244218/)

Boyle PA, Yu L, Schneider JA, Wilson RS, Bennett DA. Scam Awareness Related to Incident Alzheimer Dementia and Mild Cognitive Impairment: A Prospective Cohort Study. *Ann Intern Med.* 2019;170(10):702-709. doi:10.7326/M18-2711 [PMID 30986826](https://pubmed.ncbi.nlm.nih.gov/30986826/)

Browning, C. and Finke, M., 2015. Cognitive ability and the stock reallocations of retirees during the Great Recession. *Journal of Consumer Affairs*, 49(2), pp.356-375.

Burgdorf J, Roth DL, Riffin C, Wolff JL. Factors Associated With Receipt of Training Among Caregivers of Older Adults. *JAMA Intern Med.* 2019;179(6):833-835. doi:10.1001/jamainternmed.2018.8694 [PMID 30958503](https://pubmed.ncbi.nlm.nih.gov/30958503/)

Cabeza R, Albert M, Belleville S, et al. Maintenance, reserve and compensation: the cognitive neuroscience of healthy ageing [published correction appears in *Nat Rev Neurosci.* 2018 Dec;19(12):772] [published correction appears in *Nat Rev Neurosci.* 2018 Dec;19(12):772]. *Nat Rev Neurosci.* 2018;19(11):701-710. doi:10.1038/s41583-018-0068-2. [PMID 30305711](https://pubmed.ncbi.nlm.nih.gov/30305711/)

INTERNAL USE ONLY – NOT FOR DISTRIBUTION

CAPRA-NBER Oct. 7, 2022, Executive Summary

Chandra A, Coile C, and Mommaerts C. What Can Economics Say About Alzheimer's Disease?. No. w27760. National Bureau of Economic Research, 2020. doi: [10.3386/w27760](https://doi.org/10.3386/w27760)

Chang, M. and Ko, A., 2021. Marital Transitions, Housing, and Long-Term Care in Old Age. *Working Paper*

Coe NB, Zamarro G. Retirement effects on health in Europe. *J Health Econ.* 2011;30(1):77-86. doi:10.1016/j.jhealeco.2010.11.002 [PMID 21183235](https://pubmed.ncbi.nlm.nih.gov/21183235/)

Coe NB, von Gaudecker HM, Lindeboom M, Maurer J. The effect of retirement on cognitive functioning. *Health Econ.* 2012;21(8):913-927. doi:10.1002/hec.1771 [PMID 21818822](https://pubmed.ncbi.nlm.nih.gov/21818822/)

Coe NB, Skira MM, Larson EB. A Comprehensive Measure of the Costs of Caring for a Parent: Differences According to Functional Status. *J Am Geriatr Soc.* 2018;66(10):2003-2008. doi:10.1111/jgs.15552 [PMID 30222183](https://pubmed.ncbi.nlm.nih.gov/30222183/)

Cuddy E, Currie J. Treatment of mental illness in American adolescents varies widely within and across areas. *Proc Natl Acad Sci U S A.* 2020;117(39):24039-24046. doi:10.1073/pnas.2007484117 [PMID 32958646](https://pubmed.ncbi.nlm.nih.gov/32958646/)

Gandhi, A., 2019. Picking your patients: Selective admissions in the nursing home industry. Available at [SSRN 3613950](https://ssrn.com/abstract=3613950).

Grill JD, Raman R, Ernstrom K, et al. Short-term Psychological Outcomes of Disclosing Amyloid Imaging Results to Research Participants Who Do Not Have Cognitive Impairment. *JAMA Neurol.* 2020;77(12):1504-1513. doi:10.1001/jamaneurol.2020.2734 [PMID 32777010](https://pubmed.ncbi.nlm.nih.gov/32777010/)

Hackmann, M.B., Kolstad, J.T. and Kowalski, A.E., 2015. Adverse selection and an individual mandate: When theory meets practice. *American Economic Review*, 105(3), pp.1030-66. doi: [10.1257](https://doi.org/10.1257)

Hurd MD, Martorell P, Delavande A, Mullen KJ, Langa KM. Monetary costs of dementia in the United States. *N Engl J Med.* 2013;368(14):1326-1334. doi:10.1056/NEJMsa1204629 [PMID 23550670](https://pubmed.ncbi.nlm.nih.gov/23550670/)

Hsu JW, Willis R. Dementia Risk and Financial Decision Making by Older Households: The Impact of Information. *J Hum Cap.* 2013;2013:45. doi:10.2139/ssrn.2339225 [PMID 25525476](https://pubmed.ncbi.nlm.nih.gov/25525476/)

Jack CR Jr, Knopman DS, Jagust WJ, et al. Tracking pathophysiological processes in Alzheimer's disease: an updated hypothetical model of dynamic biomarkers. *Lancet Neurol.* 2013;12(2):207-216. doi:10.1016/S1474-4422(12)70291-0 [PMID 23332364](https://pubmed.ncbi.nlm.nih.gov/23332364/)

Keane MP, Ketcham JD, Kuminoff N, & Neal T. Evaluating Consumers' Choices of Medicare Part D Plans: A Study in Behavioral Welfare Economics (March 2019). NBER Working Paper No. w25652. Doi: [10.3386/w25652](https://doi.org/10.3386/w25652)

Kelley, A., 2016. The Burden of Healthcare Costs in the Last Five Years of Life (FR419B). *Journal of Pain and Symptom Management*, 51(2), pp.352-353. <https://doi.org/10.1016/j.jpainsymman.2015.12.199>

Korniotis, G.M. and Kumar, A., 2011. Do older investors make better investment decisions?. *The Review of Economics and Statistics*, 93(1), pp.244-265.

Largent EA, Abera M, Harkins K, et al. Family members' perspectives on learning cognitively unimpaired older adults' amyloid- β PET scan results. *J Am Geriatr Soc.* 2021;69(11):3203-3211. doi:10.1111/jgs.17362 [PMID 34252201](#)

Largent EA, Karlawish J. Preclinical Alzheimer Disease and the Dawn of the Pre-Caregiver. *JAMA Neurol.* 2019;76(6):631-632. doi:10.1001/jamaneurol.2019.0165 [PMID 30855658](#)

National Center for Health Statistics. Health, United States, 2017: With special feature on mortality. Hyattsville, MD. 2018. [PMID 30702833](#)

Oster E, Shoulson I, Dorsey ER. Optimal Expectations and Limited Medical Testing: Evidence from Huntington Disease: Corrigendum. *Am Econ Rev.* 2016;106(6):1562-1565. doi:10.1257/aer.106.6.1562 [PMID 29547253](#)

Rohwedder S, Willis RJ. Mental Retirement. *J Econ Perspect.* 2010;24(1):119-138. doi:10.1257/jep.24.1.119 [PMID 20975927](#)

Schneeweis N, Skirbekk V, Winter-Ebmer R. Does education improve cognitive performance four decades after school completion?. *Demography.* 2014;51(2):619-643. doi:10.1007/s13524-014-0281-1 [PMID 24578168](#)

Spreng RN PhD, Karlawish J Md, Marson DC Md. Cognitive, social, and neural determinants of diminished decision-making and financial exploitation risk in aging and dementia: A review and new model. *J Elder Abuse Negl.* 2016;28(4-5):320-344. doi:10.1080/08946566.2016.1237918 [PMID 27644698](#)

Stern RG, Mohs RC, Davidson M, et al. A longitudinal study of Alzheimer's disease: measurement, rate, and predictors of cognitive deterioration. *Am J Psychiatry.* 1994;151(3):390-396. doi:10.1176/ajp.151.3.390 [PMID 8109647](#)

Stern Y. What is cognitive reserve? Theory and research application of the reserve concept. *J Int Neuropsychol Soc.* 2002;8(3):448-460. [PMID 11939702](#)

Stern Y. Cognitive reserve in ageing and Alzheimer's disease. *Lancet Neurol.* 2012;11(11):1006-1012. doi:10.1016/S1474-4422(12)70191-6. [PMID 23079557](#)

Stewart CC, Yu L, Wilson RS, Bennett DA, Boyle PA. Correlates of healthcare and financial decision making among older adults without dementia. *Health Psychol.* 2018;37(7):618-626. doi:10.1037/hea0000610 [PMID 29565601](#)

Stewart CC, Yu L, Wilson RS, Bennett DA, Boyle PA. Healthcare and Financial Decision Making and Incident Adverse Cognitive Outcomes among Older Adults. *J Am Geriatr Soc.* 2019;67(8):1590-1595. doi:10.1111/jgs.15880 [PMID 30882910](#)

Valenzuela MJ. Brain reserve: A three year longitudinal neuropsychological and brain imaging examination of the "use it or lost it" principle. University of South Wales, School of Psychiatry. South Wales: University of South Wales. 2005 Jul.

INTERNAL USE ONLY – NOT FOR DISTRIBUTION

CAPRA-NBER Oct. 7, 2022, Executive Summary

Van Houtven CH, Smith VA, Stechuchak KM, et al. Comprehensive Support for Family Caregivers: Impact on Veteran Health Care Utilization and Costs. *Med Care Res Rev.* 2019;76(1):89-114.

doi:10.1177/1077558717697015 [PMID 29148338](#)

Van Houtven CH. Standing Up For My Sister. *Health Aff (Millwood).* 2022;41(10):1523-1527.

doi:10.1377/hlthaff.2022.00780 [PMID 36190889](#)

Widera E, Steenpass V, Marson D, Sudore R. Finances in the older patient with cognitive impairment:

"He didn't want me to take over". *JAMA.* 2011;305(7):698-706. doi:10.1001/jama.2011.164

[PMID 21325186](#)

Aging, Cognition, and Decision Making

Patricia Boyle, PhD
Professor of Psychiatry and Behavioral Sciences
Rush Alzheimer's Disease Center
Rush University Medical Center
Chicago, IL

Aging and decision making: a major economic and public health challenge

Older adults face many complex and impactful financial and health decisions

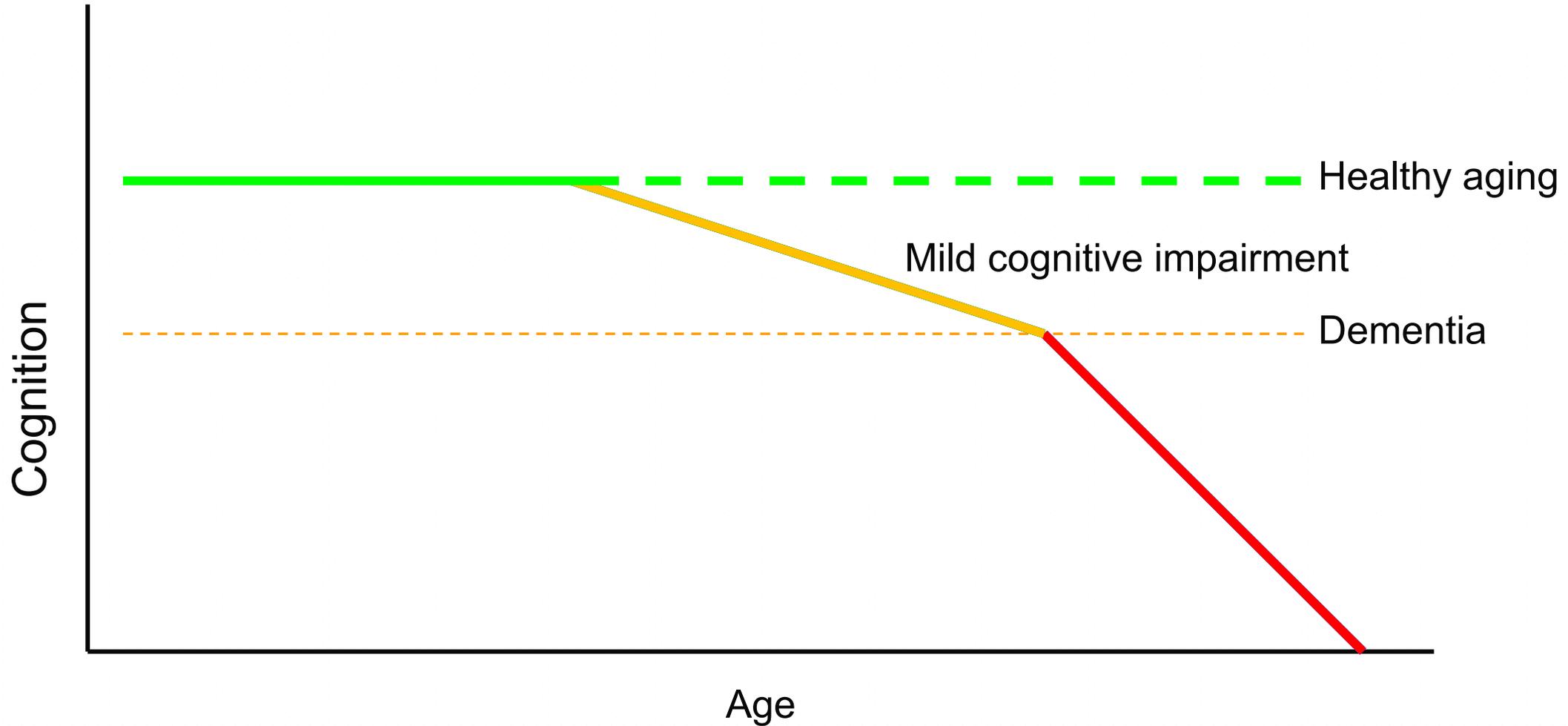
Increase in bankruptcy filings, risky credit/spending behaviors, underutilization of healthcare benefits

>5 million older adults defrauded each year; losses may exceed \$30 billion/year

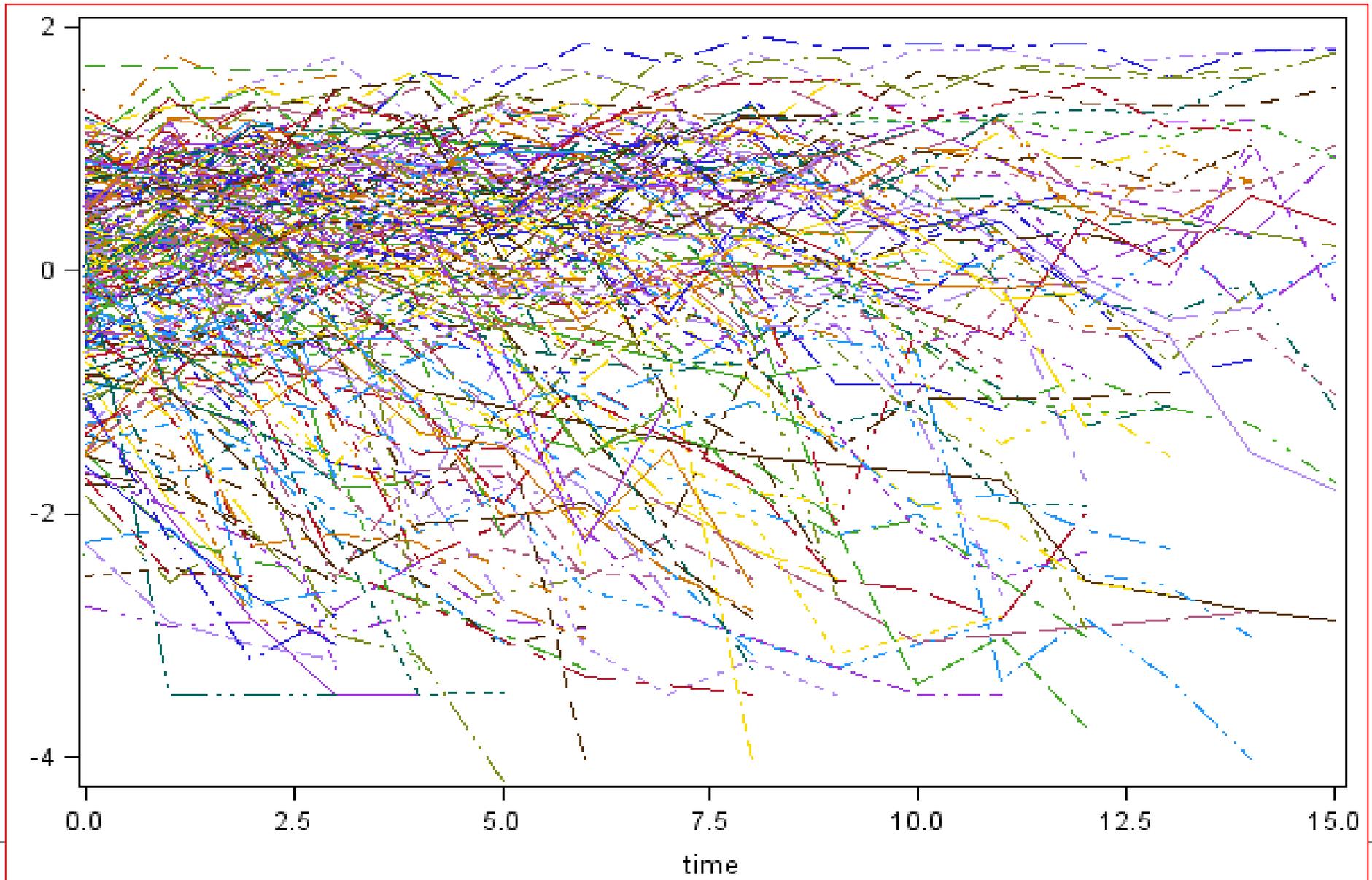
Financial losses associated with a range of adverse financial and health outcomes

- Our work: neuroscientific approach to understand how aging affects financial and health decision making, fraud and scam susceptibility
- Cohort study of aging (N>2,000), longitudinal, clinical-pathologic
- Role of cognitive aging; other causes and adverse consequences

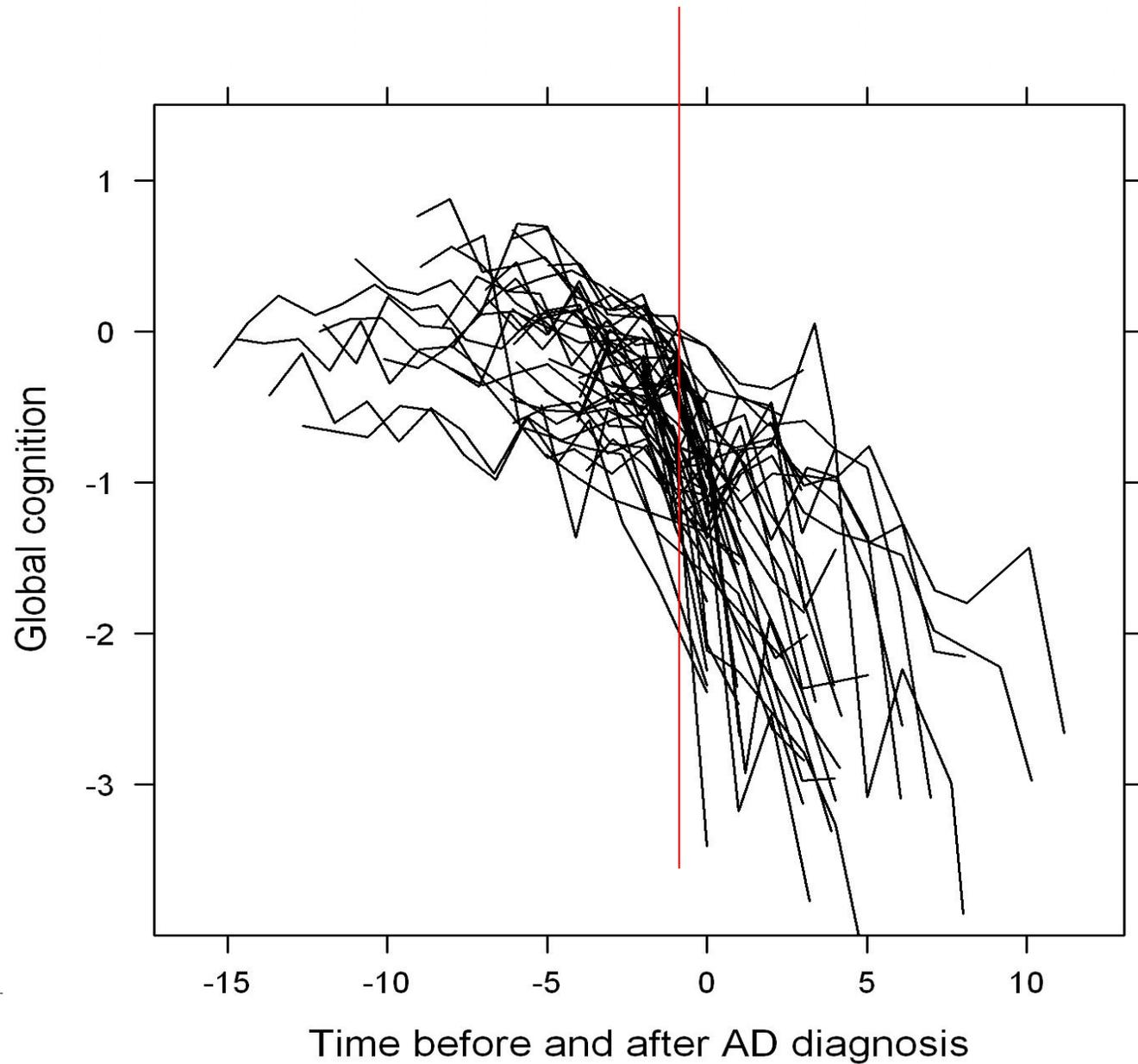
Cognitive aging: the model



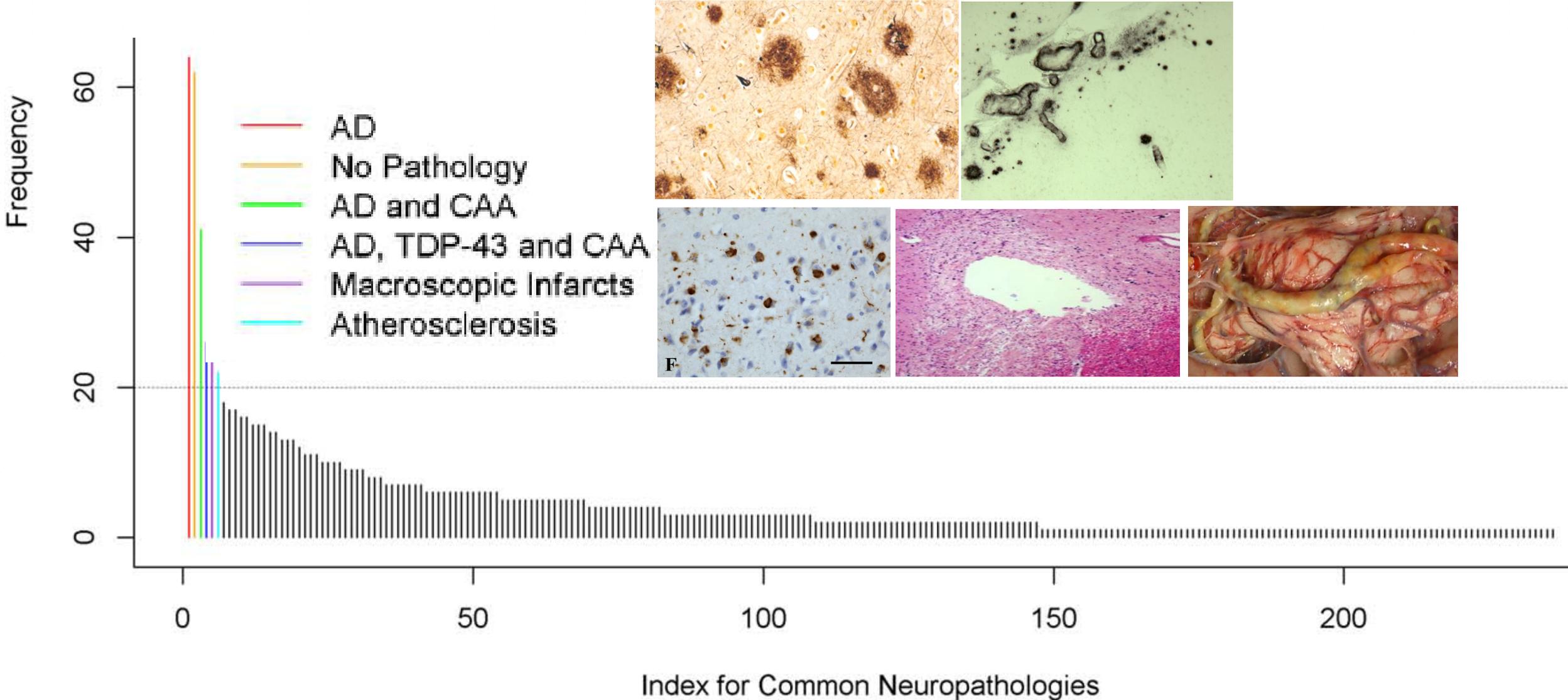
Cognitive aging: the reality



Cognitive change before and after dementia diagnosis



Biological reality: pathology is ubiquitous in the aging brain



Cognitive aging and decision making

Older adults with cognitive impairment (MCI, dementia) exhibit poor decision making

- Financial and healthcare decisions

- Scam susceptibility

- Fraud risk

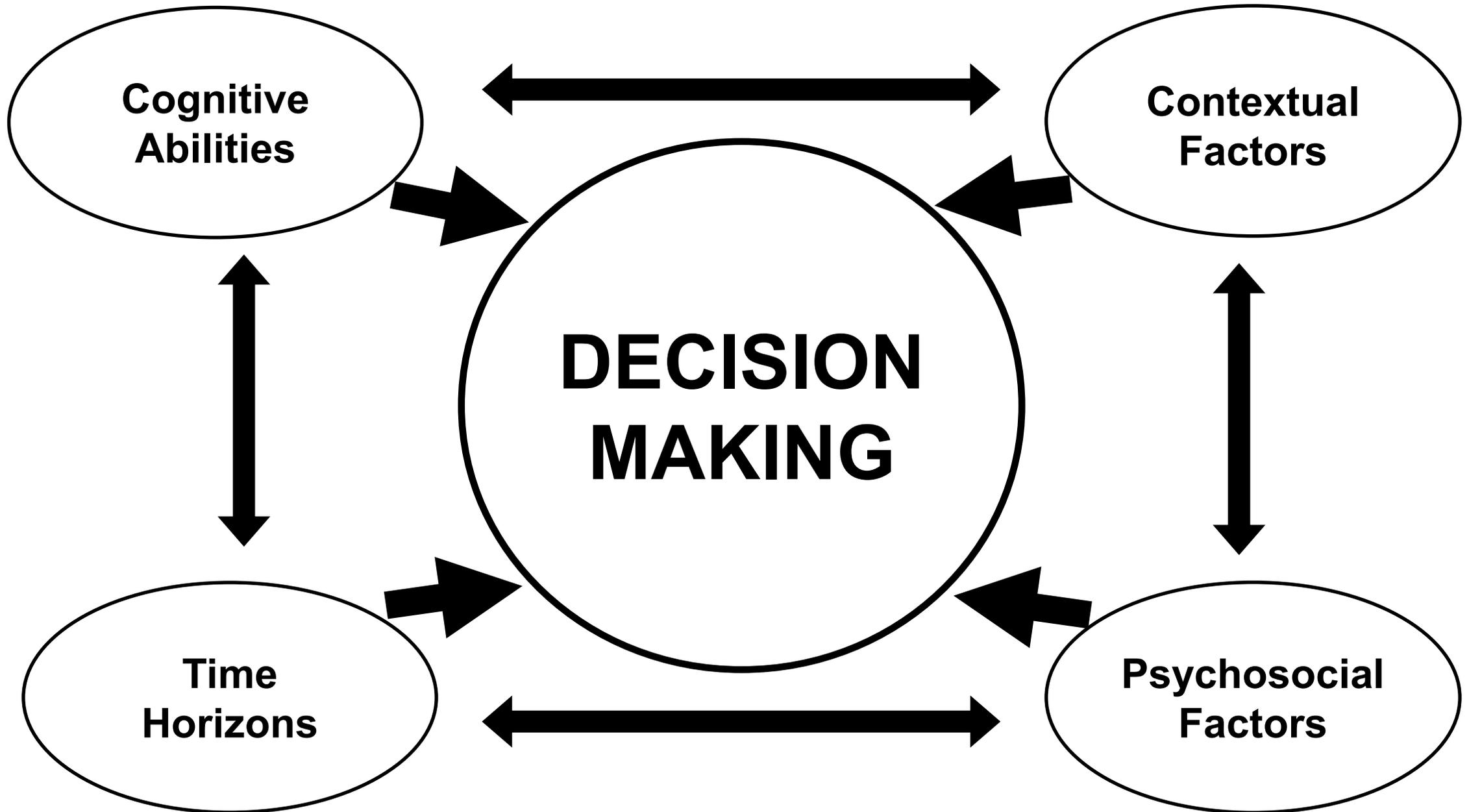
- *Many still manage own finances/affairs

BUT many cognitively intact older adults also struggle

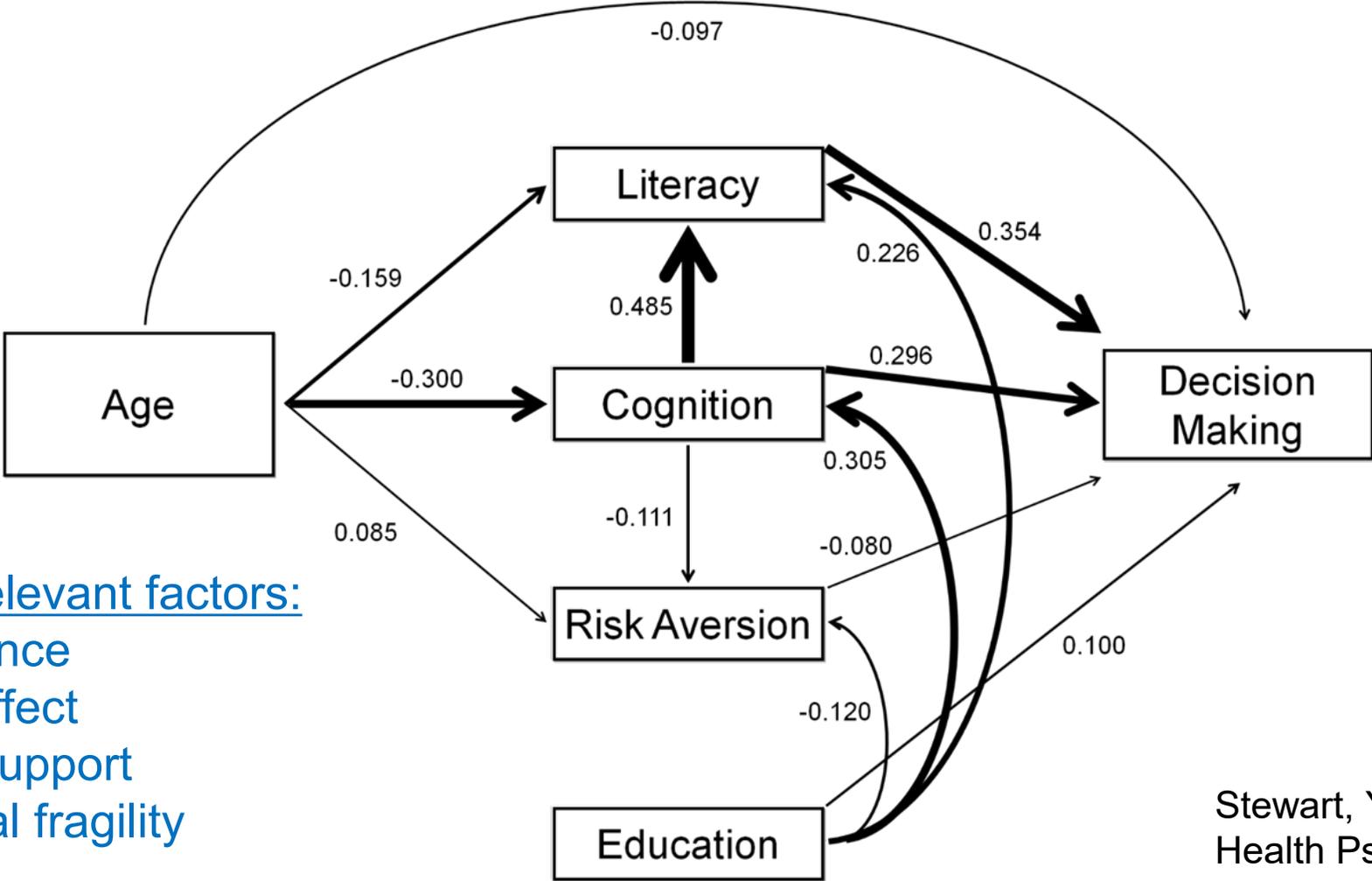
- 30-40% suboptimal performance across domains

- 8% report fraud victimization each year

Declines with advancing age



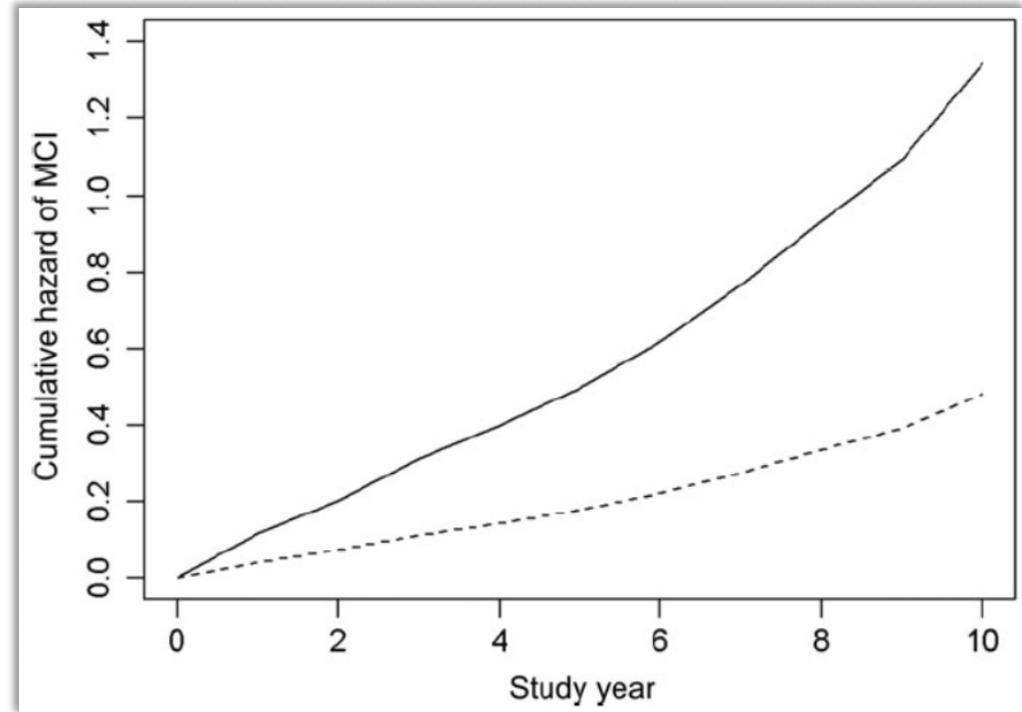
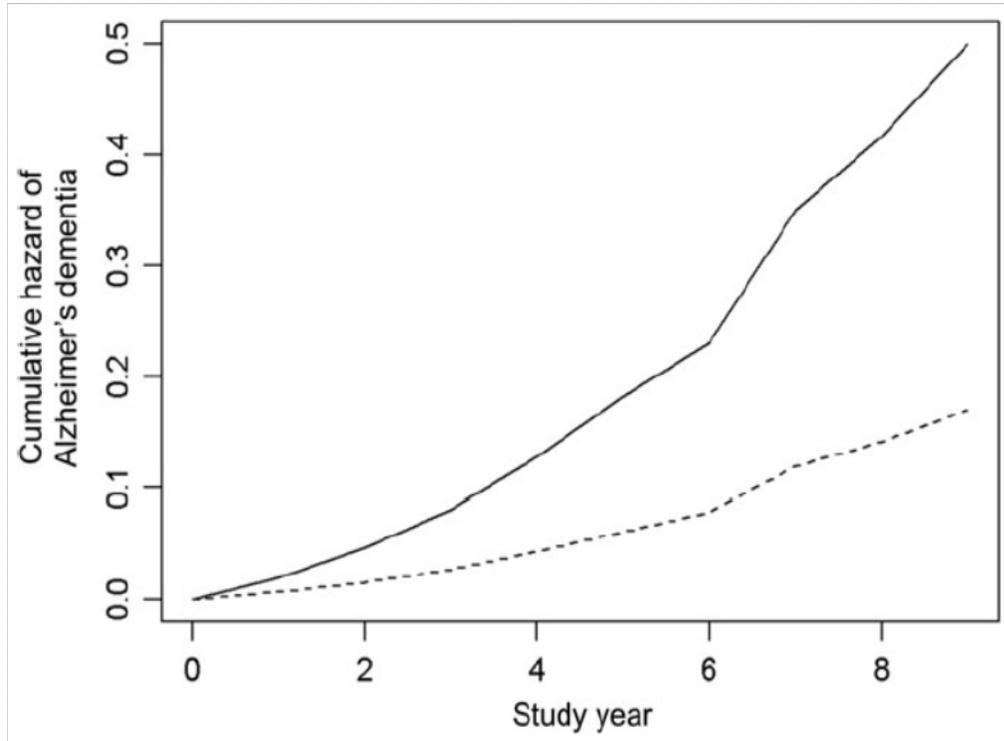
Decision making reflects a dynamic interplay among diverse resources



Other relevant factors:
Confidence
Mood/affect
Social support
Financial fragility

Stewart, Yu et al.
Health Psychol 2018

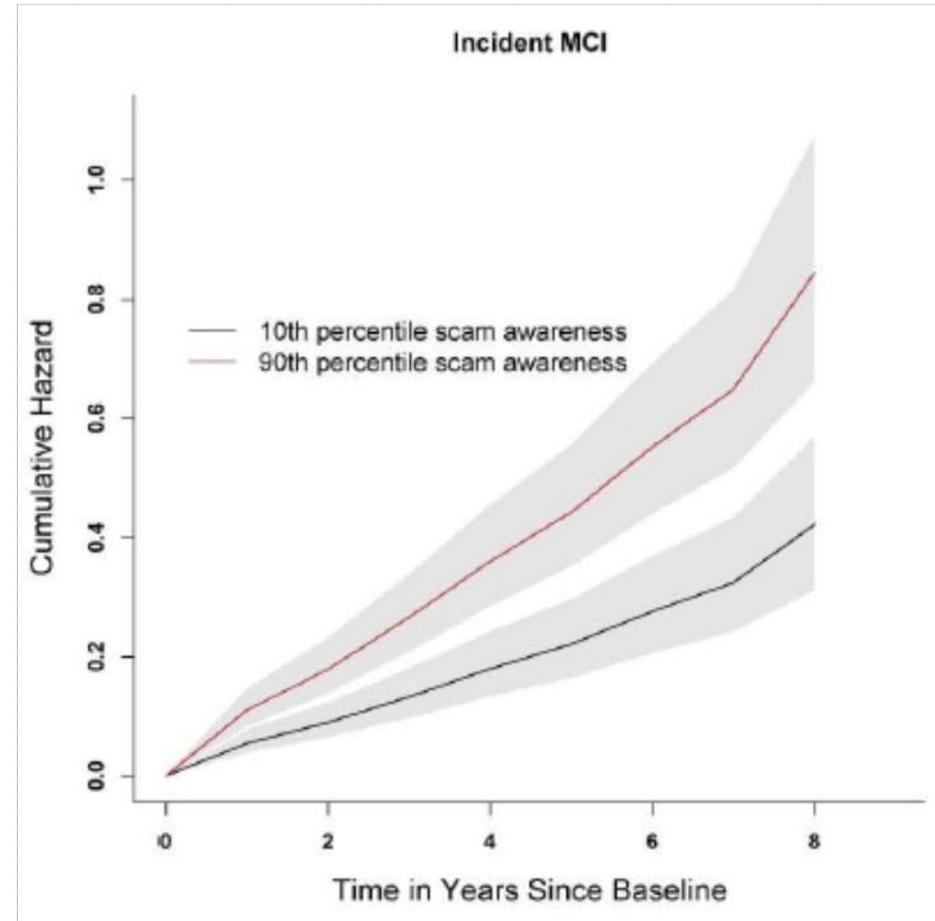
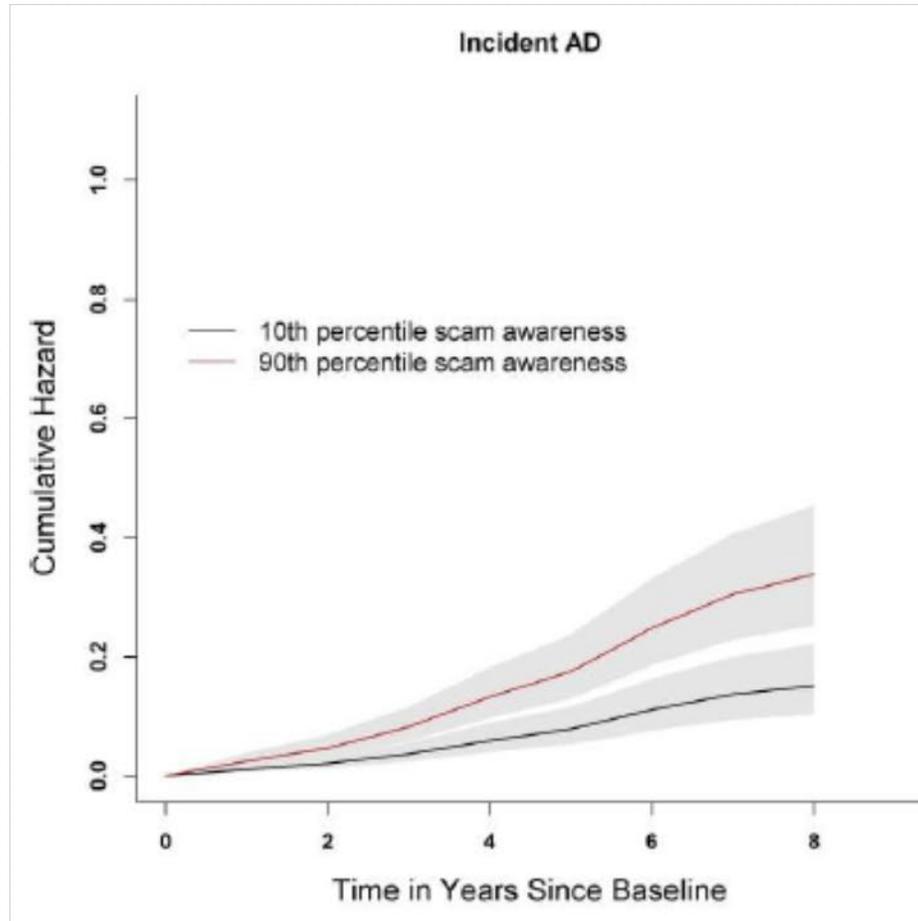
Poor decision making is a harbinger of adverse outcomes



Poor decision making ~3x more likely to develop Alzheimer's dementia or MCI

Stewart et al.
JAGS 2019

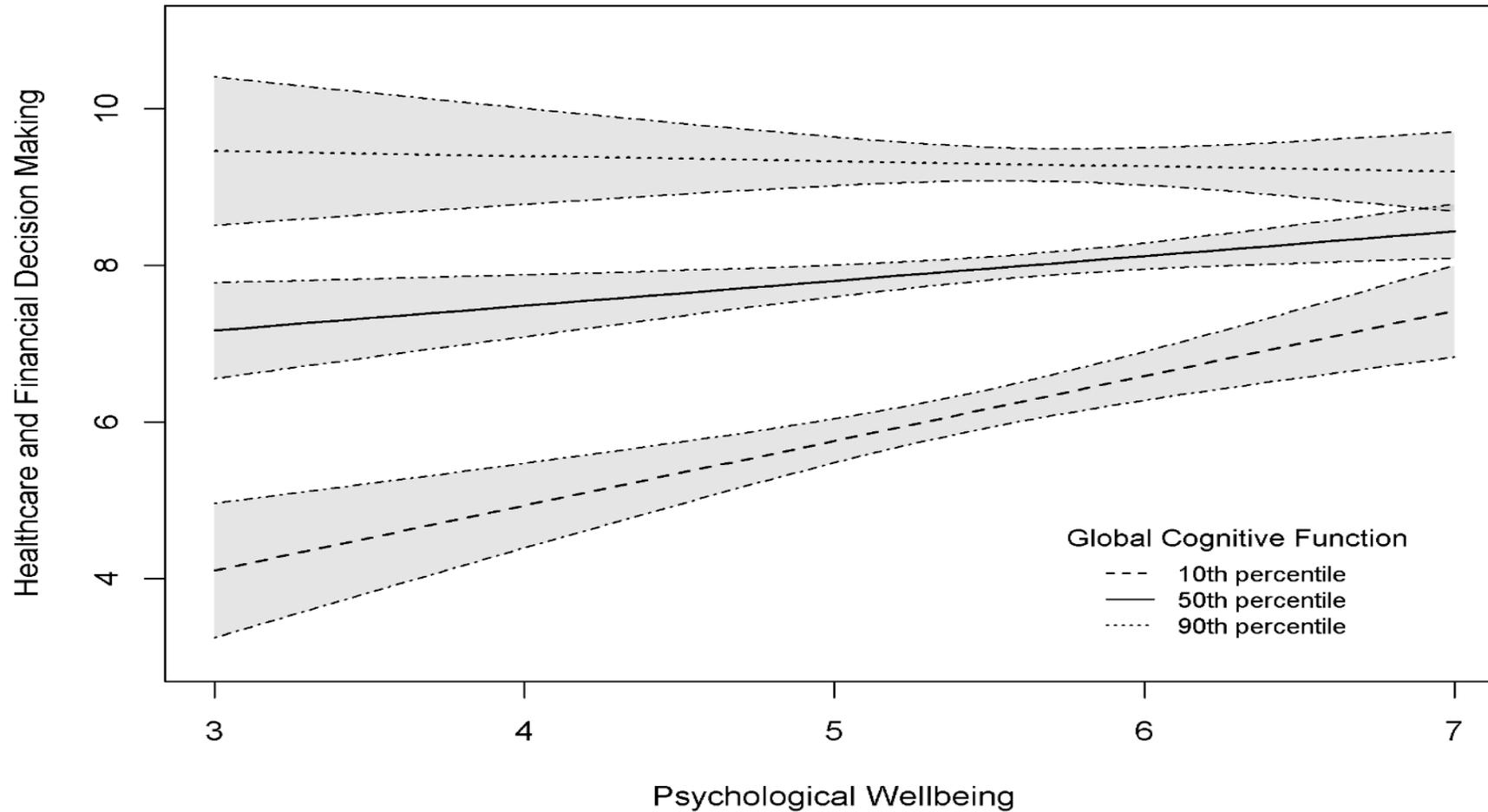
Scam susceptibility and dementia/MCI



Susceptible ~2x more likely to develop Alzheimer's dementia or MCI

Boyle et al.
Annals Internal Med 2019

What protects in the face of cognitive aging?



Other protective factors:
Cognitive activity
Social engagement/support
Technology use

Conclusions/next steps

Many older adults—including those with and without cognitive impairment—exhibit poor financial and health decision making

Cognitive aging important, but psychological, social and other factors also play a role; many modifiable

- *opportunities for novel structural/individual-level interventions

Poor decision making a very early indicator of adverse outcomes

- *earlier detection of ADRD?

- *financial monitoring tools/privacy and autonomy

- *implications for financial and health planning

Markers of Dementia and Disease Impacts

Lauren Hersch Nicholas
University of Colorado

October 7, 2022

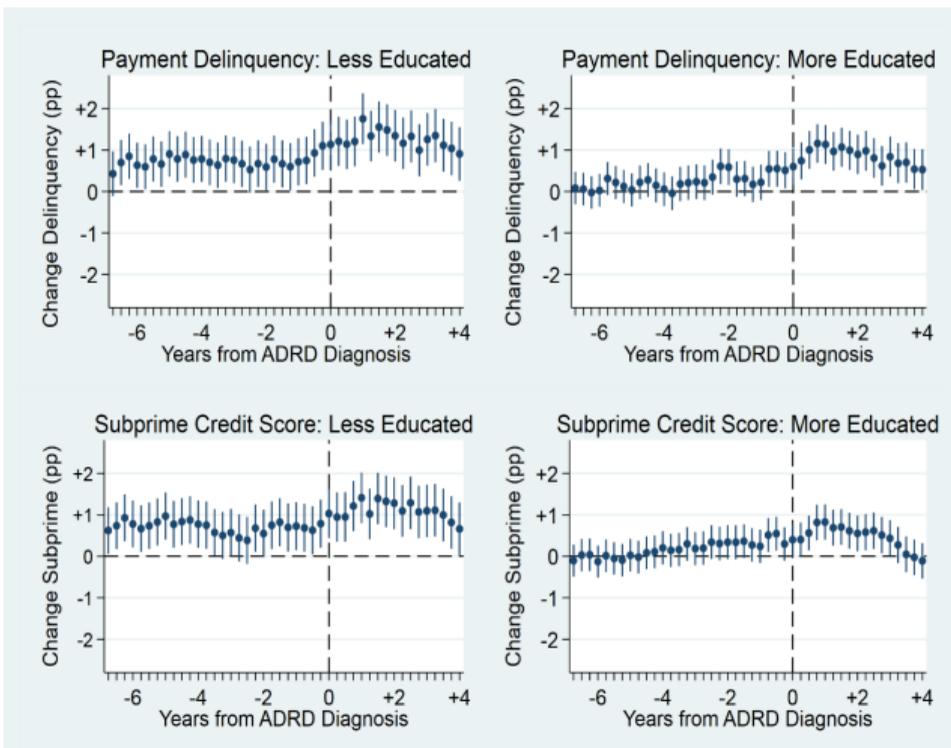
Background

- Classic dementia symptoms include erratic bill payments, risky financial decisions, and susceptibility to financial fraud, often caught late in disease progression (i.e. Boyle et al., 2012; Marson, 2001; Widera et al., 2011, Spreng et al., 2016)
- Self-reported difficulties managing money predictive of future dementia (i.e. Barnes et al., 2014)
- Patients often overstate abilities and keep inappropriate roles; 80% of decision-makers continue after decline (Hsu and Willis, 2013)

Economic Evidence: Aging, Cognition, and Financial Decision-Making

- Higher IQ/cognitive functioning associated with better stock allocations/investing behavior (Browning and Finke, 2015)
- Older investors worse at stock selection, diversification (Korniotis and Kumar, 2011)
- Older adults pay higher interest rates and more fees than younger credit users (Agarwal et al, 2007)
- Worse part D choices before and after dementia onset versus never-dementia (Keane et al., 2019)

Financial Symptoms Start Early, Especially in Lower-Education Areas

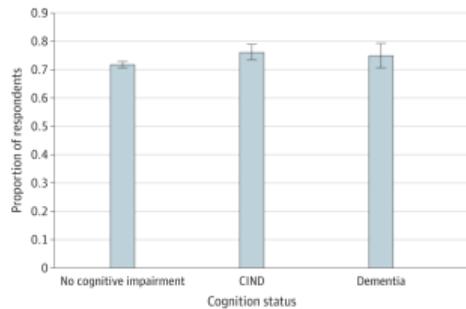


Delinquency More Likely Among those with Potentially Delayed Dx

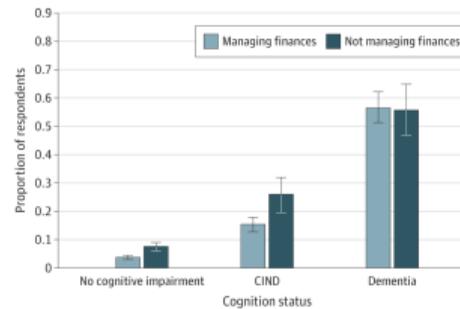
- Higher rates of financial symptoms and longer pre-diagnosis period among those whose first dementia codes appear during hospitalization (in progress)

Many Cognitively Impaired Older Adults Manage Money

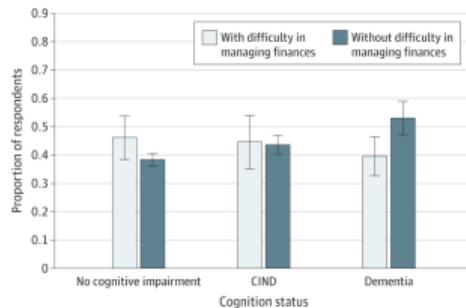
A Actively managed own money



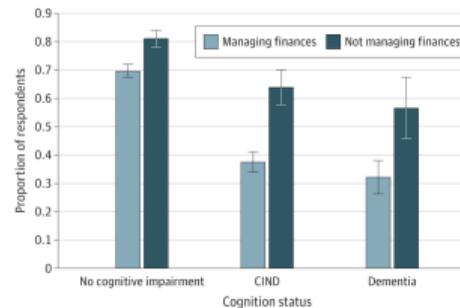
B Reported difficulty in managing own money



C Lived alone and managed own money



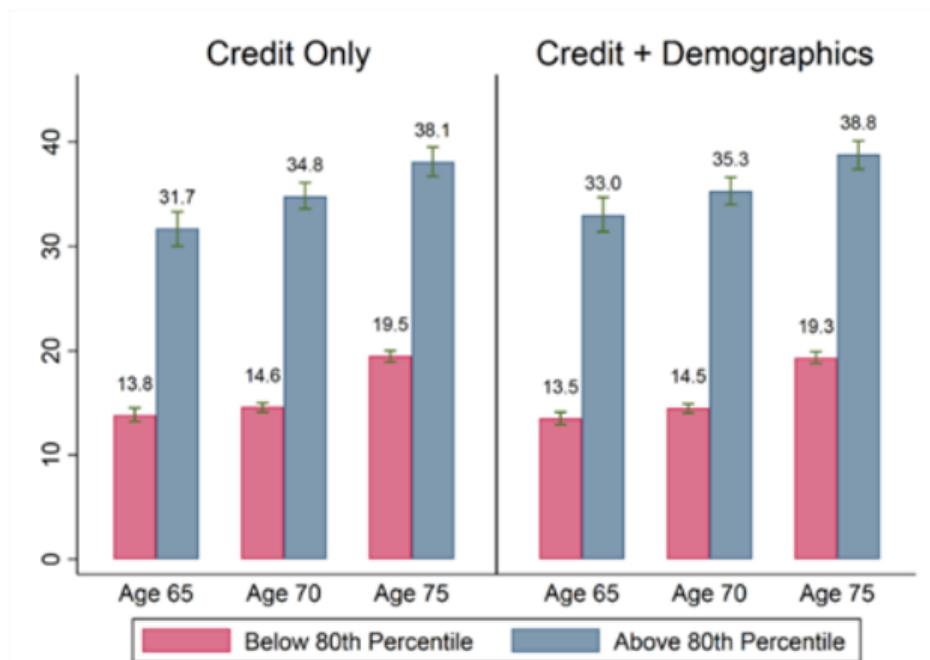
D Owned risky assets



More Rapid Dissaving Among Cognitively Impaired

- Health and Retirement Study data yields similar patterns (declines relative to never dementia, starting years prior to diagnosis) for other financial outcomes
- financial wealth, checking accounts, home ownership
- increased reliance on Medicaid and nursing home residence only after diagnosis

Financial Data for Monitoring and Diagnosis? In-Sample Prediction of Future ADRD By Credit Data Dementia Risk Score



Summary/Next Steps

- Financial symptoms emerge years prior to diagnosis and can have large impacts on households
- Few strategies to recover lost funds, must prevent loss or optimize transfer time
- How good can we get at detecting?
- What policy levers can protect/prevent losses?
- Public policy to protect financial security AND financial data
 - New types of information sharing across institutions and sectors

Cognitive Impairment, The Family and Caregivers

Kathleen McGarry
University of California, Los Angeles
and NBER

CAPRA and NBER Conference on Financial and Economic Decision-Making,
Alzheimer's Disease, and Outcomes over the Lifecycle, October 6-7, 2022.

Be Nice To Your Kids
THEY'LL CHOOSE
Your Nursing Home



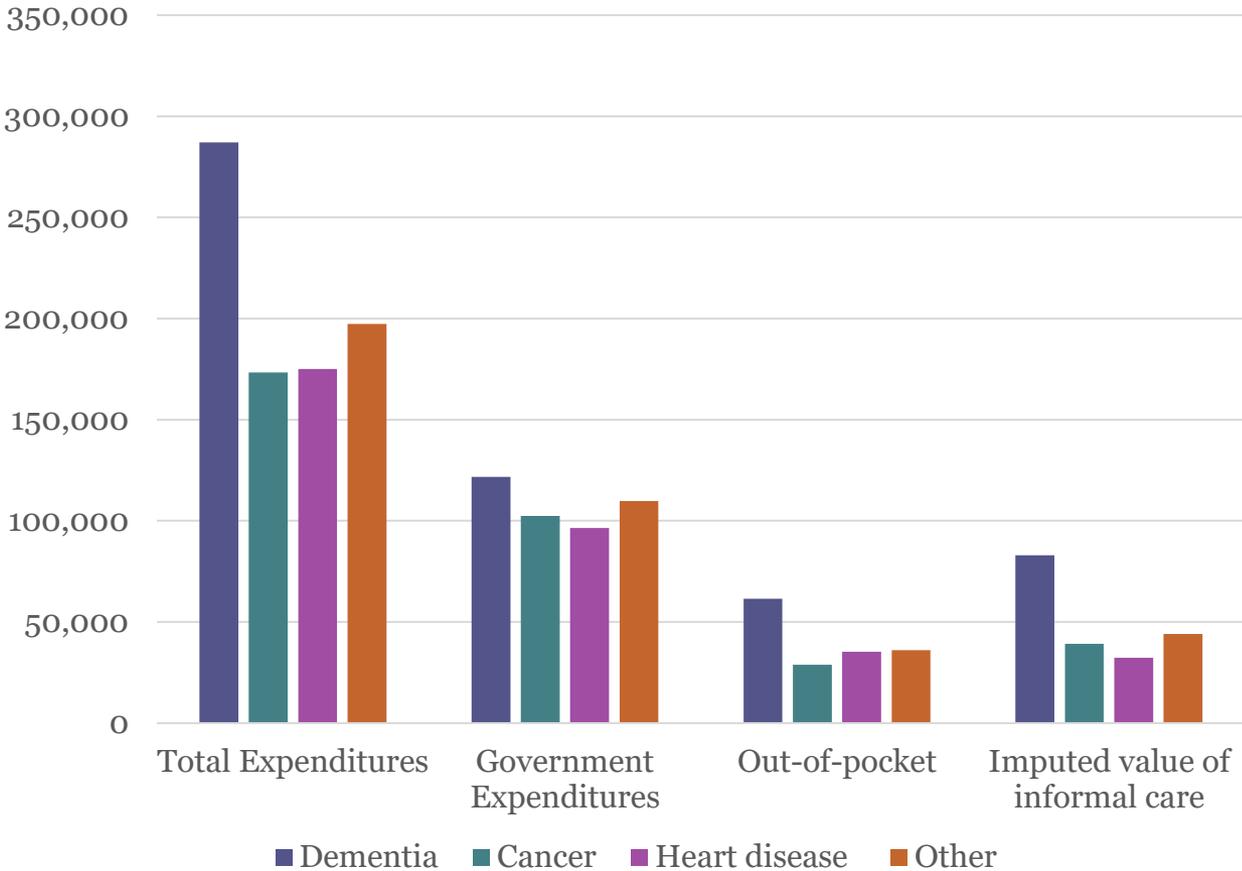
Potential Costs to Family

- Out-of-pocket costs for formal care
 - Formal care, home adaptation
- Labor market effects
 - Lost wages
 - Lower wage growth, lack of investment in job
 - Job / career changes to allow more flexibility
 - Lost pension / decreased pension wealth
 - Difficulty re-entering the labor market
- Health effects
 - Physical burden
 - Emotional burden / emotional benefit
- Effects on impaired individual
 - Do family caregivers provide better or worse care?
 - What is preferred by the recipient?

Burden on informal caregivers

- *Being a caregiver affected my stress levels thus my sleep and mood, affected my finances, affected my job... I would do it all again as my parents were loving and generous people.*
- *I can tell you that caregiving retards your career opportunities. I had to decline company travel, working long hours, and doing activities that required me to be gone for long and/or unpredictable lengths of time...peers are now making tens of thousands of dollars more than I am, and I feel increasingly disenfranchised.*
- *Ms. Washington found herself performing high-level nursing tasks, like administering antibiotics three times a day through a PICC line — a thin tube that leads from veins in the arm to the veins near the heart. “My hands were shaking,” she said as she remembered apprehensively pushing in the drugs for the first time and feeling the weight of keeping her husband alive.*

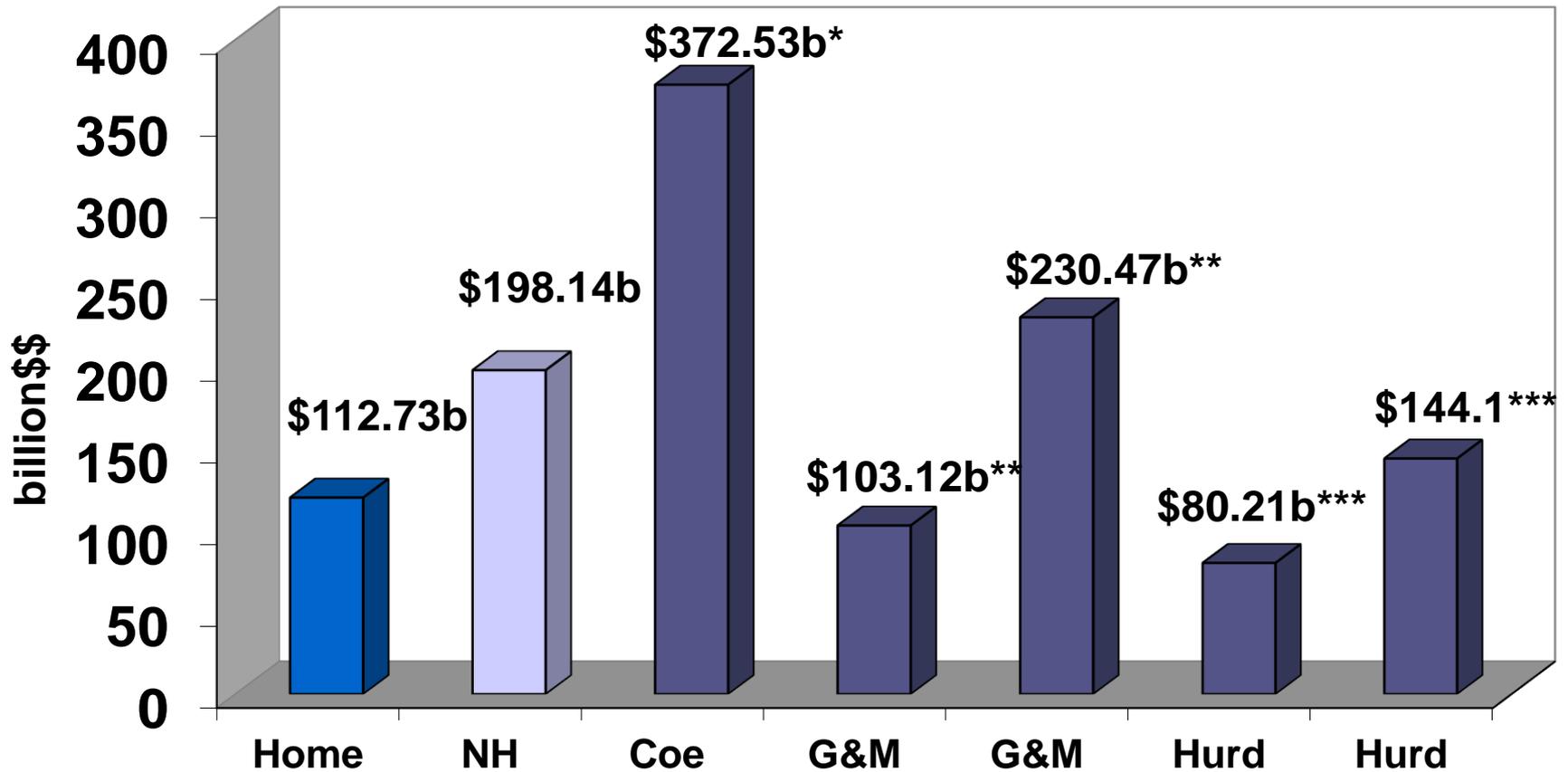
End of Life Spending by Cause of Death



SOURCE: Kelley, et al. 2016



Comparative Cost of Care



SOURCE: Heath USA, 2017 for formal care, for informal care: Coe et al. (2018), ** Gruber and McGarry (2022), ***Hurd et al. informal care, all inflated to 2022 dollars.

Who provides Care

- Caregivers exhibit greater labor market attachment
 - Prior to care: Higher probability of working, higher earnings, more hours, more experience, longer tenure
- Caregivers have “better” jobs
 - More likely to have pensions, health insurance, more vacation time
- More advantaged w/r/t demographics
 - More schooling, better health, more likely to be married,
- Greater household resources
 - Greater hh income, wealth, spouse’s earnings



Long-term Effects

	Caregivers (N=837)	Non-Caregivers (N=1390)
	Observation	Observation
	First	First
Net Wealth (financial)	154,894	101,512
Net Wealth (non-housing)	354,589	294,527
Net Wealth (total)	472,970	412,442
Household Income	90,124	95,142
Earnings > 0	40,021	36,396
Work 0/1	0.72	0.71
Hours > 0	39.11	37.51
Fair/Poor Health	0.13	0.15

Long-term Effects

	Caregivers (N=837)		Non-Caregivers (N=1390)	
	Observation		Observation	
	First	Last	First	Last
Net Wealth (financial)	154,894	174,533	101,512	190,241
Net Wealth (non-housing)	354,589	459,510	294,527	499,513
Net Wealth (total)	472,970	698,34	412,442	703,353
Household Income	90,124	70,713	95,142	76,508
Earnings > 0	40,021	26,449	36,396	28,701
Work 0/1	0.72	0.24	0.71	0.25
Hours > 0	39.11	27.31	37.51	27.63
Fair/Poor Health	0.13	0.21	0.15	0.24

Caregiving's Impact on Well-being

- Current impact
 - 8% reduction in the probability of working
 - 4% reduction in hours
 - Reductions exist across demographic groups
- Impacts still felt at age 65:
 - 18-25% lower probability of work
 - 20-25% reduction in hours worked
 - 25-30% lower earnings
- Impacts still felt at age 70:
 - Lower assets
 - Increase in probability of fair or poor health

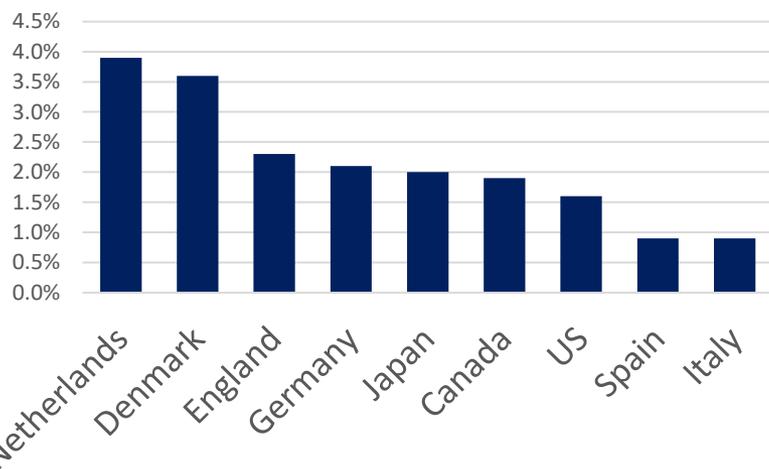
The Future of Family Care

- Obstacles
 - Declines in fertility
 - Changes in disease specific mortality
 - Greater labor force participation for women
 - Migration
 - Increases in divorce and blended families
- Positive developments
 - Pay for informal caregivers from public programs
 - Paid family leave
 - Technological advances
 - Medical advances
 - HCBS
 - Respite care and emotional support

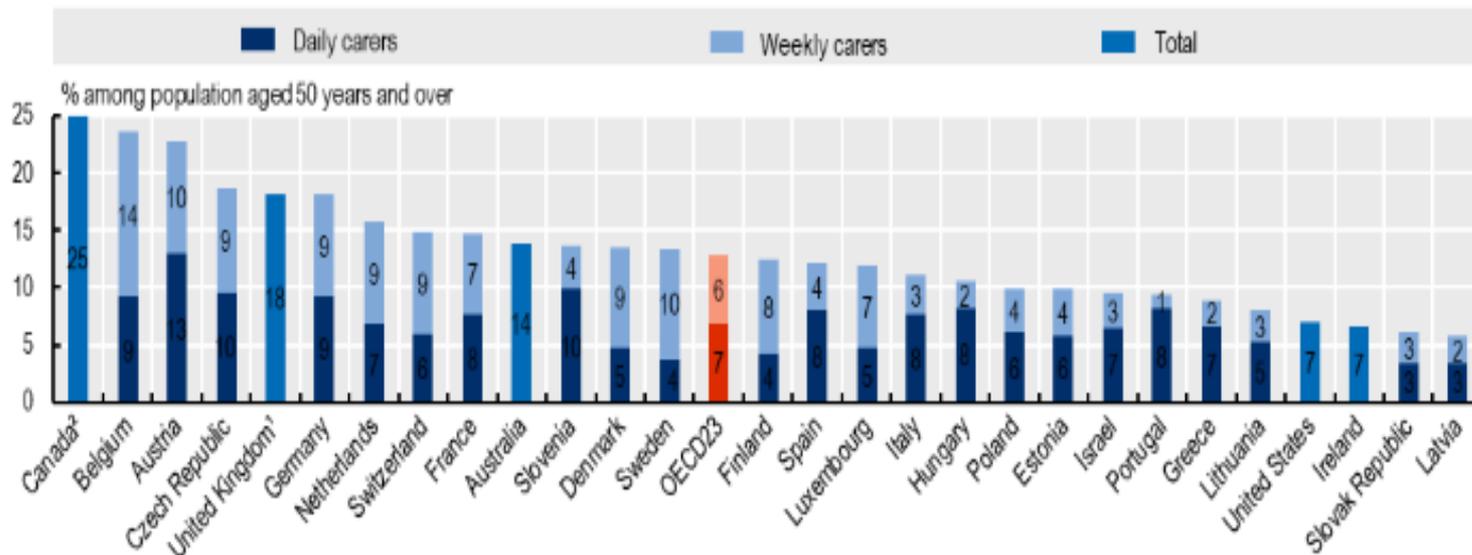
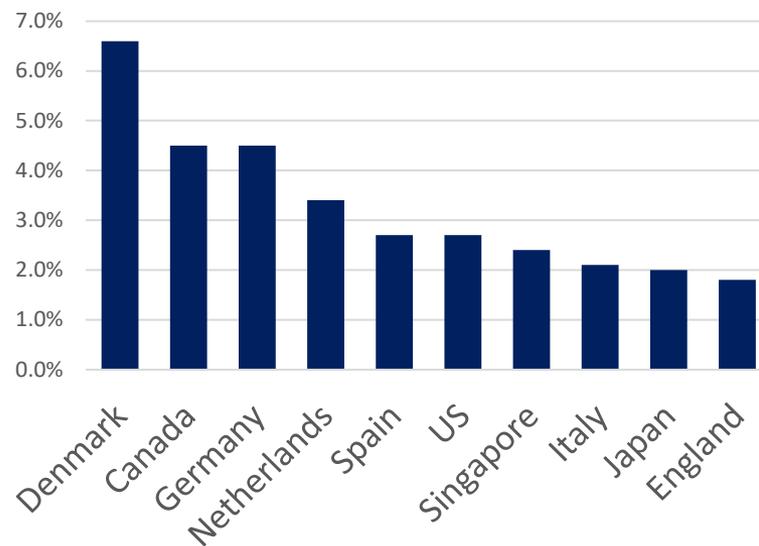
Questions

- Unrecognized help
 - Children / neighbors bring groceries, run errands, medical appointments
 - Reliance on spouses
 - Use of automatic / preset
 - Automatic payments, Annuities / Defined Benefit plans
 - Subscriptions
- Role of siblings
 - Sharing caregiving or direct transfers
 - Alternatives forms of support
 - Disagreement of types of care

Share of GDP Spent on LTC



Share of Elderly in NH



Cognitive Reserve

Kevin Thom
University of Wisconsin - Milwaukee

CAPRA-NBER Conference on
Financial and Economic Decision-Making,
Alzheimer's Disease, and Outcomes over the Lifecycle

OCTOBER 7, 2022

Reserve: Motivation

- Similar events may trigger different responses in cognitive functioning across individuals: (e.g. stroke, head trauma, etc).
- Post-mortem studies reveal significant variation in observed pathology of Alzheimer's disease (AD) progression among individuals with similar cognitive functioning at death.
- Heterogeneity in evolution of cognitive performance with age in healthy individuals
- Suggests differences across individuals in characteristics or processes that affect cognitive health.

Reserve: Motivation

- Multiple related concepts here, with some subtle differences:
- Cabeza et al (2018) offers some useful definitions
 - ▶ **Reserve:** *a cumulative improvement ... of neural resources that mitigates the effects of neural decline caused by ageing or age-related diseases.*
 - ▶ **Maintenance:** *preservation of neural resources, which entails ongoing repair and replenishment of the brain in response to damage incurred ... owing to 'wear and tear'*
 - ▶ **Compensation:** *cognition-enhancing recruitment of neural resources in response to relatively high cognitive demand*

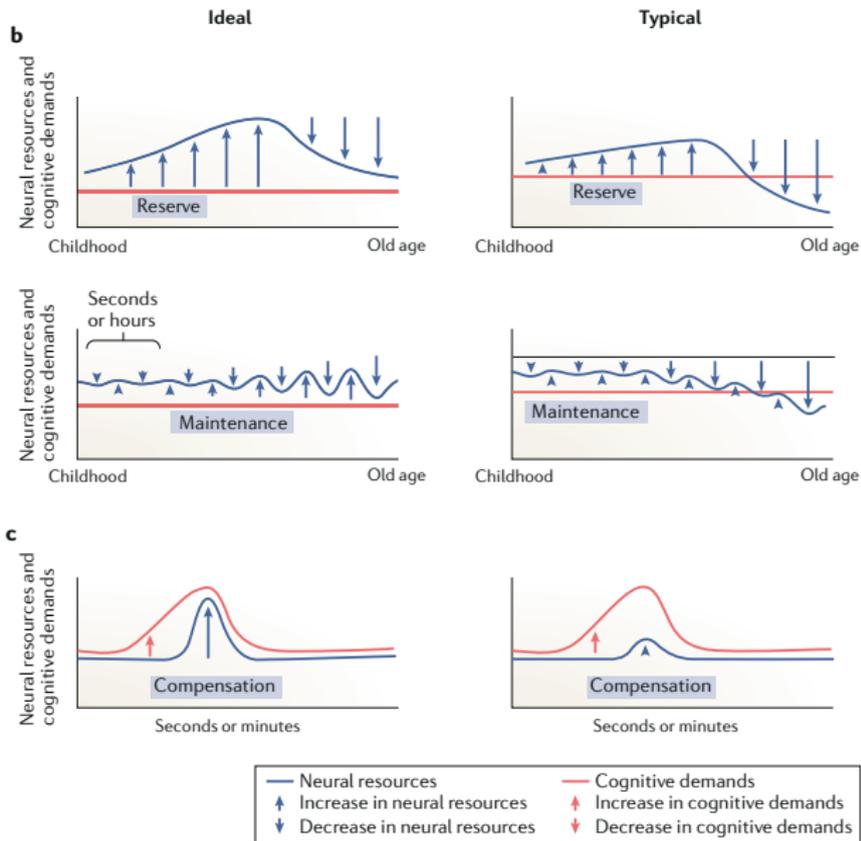


Figure: From Cabeza et al. 2018

Cognitive Reserve: The Basic Idea

- Stern (2002, 2012) makes a distinction:
 - ▶ Brain reserve capacity (BRC): e.g. differences in brain size, synapse count.
 - ▶ Cognitive reserve (CR): More resilient brains may more easily engage brain networks or cognitive paradigms that are less susceptible to disruption.

Possible Sources of Cognitive Reserve

- Educational Attainment
- Work / Occupational
- Stimulating Leisure Activities

Levels and Rates of Decline

- Higher levels of educational attainment associated with:
 - ▶ Lower prevalence and incidence of ADRD, improved cognitive performance (Stern et al 1994, Valenzuela et al 2005, Stern 2012)
 - ▶ Faster decline conditional on diagnosis (Stern 2002)
- Stern (2002) offers a possible explanation:
 - ▶ More educated individuals with greater CR can sustain more brain pathology before presenting clinical evidence of ADRD.
 - ▶ Once diagnosed, high CR individuals are further along in disease progression, closer to end-stage.

Causality

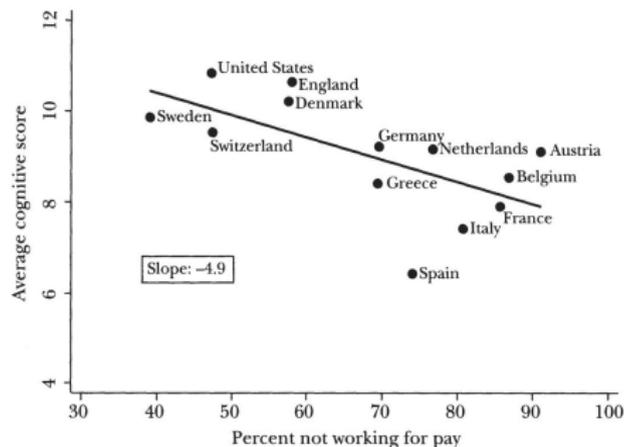
- Educational Attainment, Work Activities, Leisure Activities - related to cognitive decline
- Are these causal relationships?
- Number of studies try use experimental or plausibly exogenous variation to get at this

Causal Evidence

- Changes in compulsory schooling positively related to memory, executive functioning (Banks and Mazzonna 2012, Schneeweis et al 2014)
- Reforms to pension programs / variation in eligibility
 - ▶ Negative effects of retirement on cognition (Rohwedder and Willis 2010, Bonsang et al 2012, Atalay 2019)
 - ▶ Interesting contrast to positive effects on overall health (Coe and Zamarro 2011)
 - ▶ Coe et al (2012) - employer early retirement windows as IV, find no (causal) effect on cognition for white-collar workers, evidence of a positive effect for blue-collar workers.

Work and Cognitive Performance

Cognition by Percent Not Working for Pay, 60–64 Year-Old Men and Women, Weighted



- Rohwedder and Willis (2010): Use features of retirement policy across countries as instrumental variables for work status.
- Estimate that retirement (not working for pay) reduces performance on cognition test by 1.5 standard deviations.

Pathways Forward: Causality

- (1) Treatment effect heterogeneity
- Interpret reported effects as LATEs - who are the compliers?
- When we extrapolate these results out of sample, who are the most likely to be affected?

Pathways Forward: Causality

- (2) Timing
- Evidence on treatments occurring later in life (retirement incentives), or earlier in life (schooling incentives)
- Interesting to understand where changes CR activities have different effects at different periods in life
- Literature in child development on the importance of “critical stages” - early interventions may be more effective.

Pathways Forward: Mechanisms

- Suppose that we grant that work / occupational tasks / other activities matter
- What is it about these activities that build reserve?
- Critical policy question
- Is complex reason more or less important than routine v.s. non-routine distinction?
- Do stressful situations develop capacity for alternate paradigms / network activation?

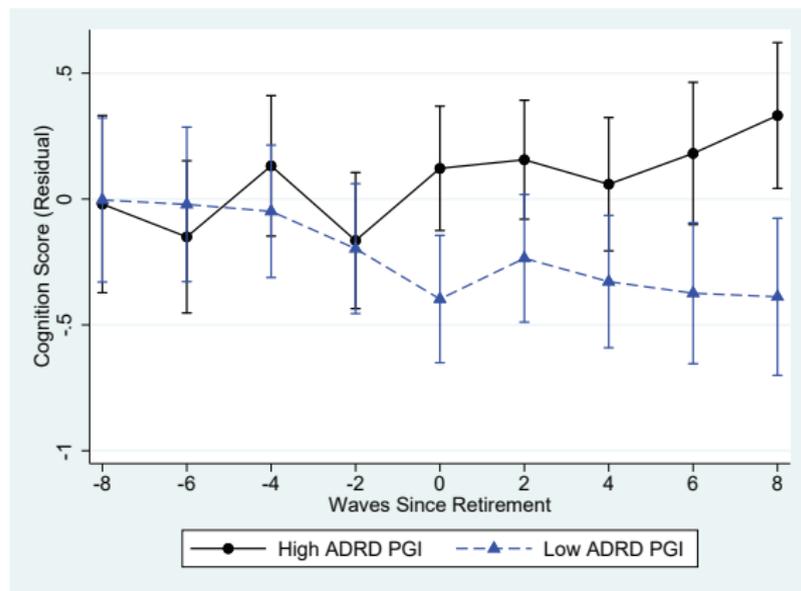
Pathways Forward: Measurement

- Advances in biomarkers to detect ongoing pathology in ADRD
- For example - cerebrospinal fluid tests for tau / amyloid plaques
- Developing data / survey platforms that link these measurements with behavioral outcomes critical
- Are there behavioral correlates of the kinds of alternate brain networks discussed in this literature? Wild speculation:
 - ▶ Do individuals engaging different networks approach problems differently?
 - ▶ Response times, Revisions, eye movement, etc.

Pathways Forward: Genetics

- APOE of course
- But also polygenic scores for ADRD and Educational Attainment (both excluding APOE), which predict cognitive decline
- Potentially offer ways to test hypotheses about cognitive reserve - looking at how environmental factors or choices moderate relationship between these genetic predictors and cognitive outcomes.

Pathways Forward: Genetics



- Example from (Jeong, Papageorge, Skira, Thom 2022)

Pathways Forward: Modelling

- Rohwedder and Willis (2010): Cognitively stimulating activities respond to incentives
- Evaluating effects of changes in retirement policies, or changing industrial structure may require modeling how individuals endogenously change their exposure to cognitive stimulation.
- Economists have a lot to learn from other disciplines
- Economists can also contribute framework for thinking about behavioral responses to policies, and an evaluation of welfare effects over the life-cycle.

Economic decisions in the context of risk knowledge: genetics & early diagnosis

Jason Karlawish, MD

University of Pennsylvania

Penn Memory Center

Penn Program for Precision Medicine for the Brain (P3MB)

The New York Times

HEALTH

Alzheimer's Tests Soon May Be Common. Should You Get One?



By Gina Kolata

Published Dec. 20, 2019 Updated Dec. 24, 2019

Dr. Jason Karlawish, an Alzheimer's researcher at the University of Pennsylvania, did a formal study to gauge patients' responses to learning that they had elevated levels of amyloid in their brain.

He did not see catastrophic reactions to the bad news. No one died by suicide.

Instead, many said they were taking steps to slow Alzheimer's, putting their faith in healthy diets and exercise although no lifestyle measures have been shown to have an effect.

The New York Times

Opinion

LETTERS

The Many Ways of Coping With Alzheimer's

Jan. 11, 2020

To the Editor:

As an individual with a family history of Alzheimer's, I understand the conflicts involved in assessing whether we want to know our risks of getting the disease. I took part in Dr. Jason Karlawish's study of patients' responses to the news of amyloid levels because I wanted to be able to plan for my future.

Receiving the news that there was no amyloid in my brain provided relief beyond expression. If the results had been different, however, I would have accepted them with the knowledge that I could plan for my ultimate demise in a way that would work for me and be helpful to my loved ones.

Alan N. Frankel
Bryn Mawr, Pa.

Economic decisions in the context of risk knowledge

- Risk expressed using a measure of ApoE genotype or biomarker of disease or neurodegeneration
 - ApoE in the comfort of your home
 - Biomarker tests via PET or MRI scans, spinal fluid or blood assays
- Risk of what.....?
 - Death
 - Alzheimer's disease
 - Caregiving

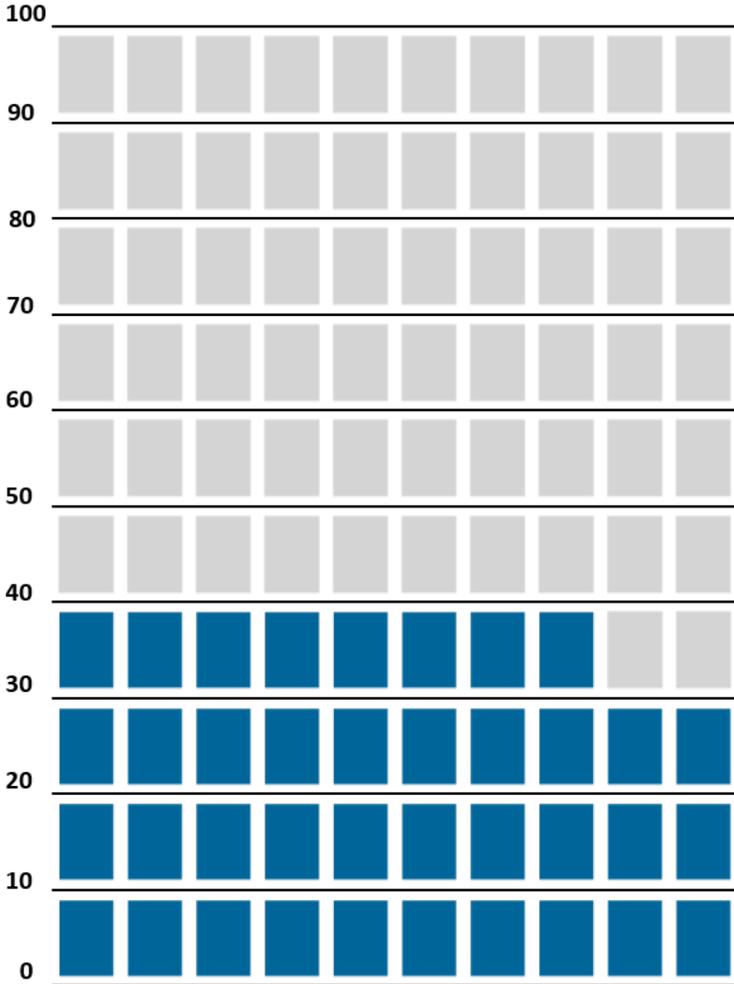


What is remaining risk?

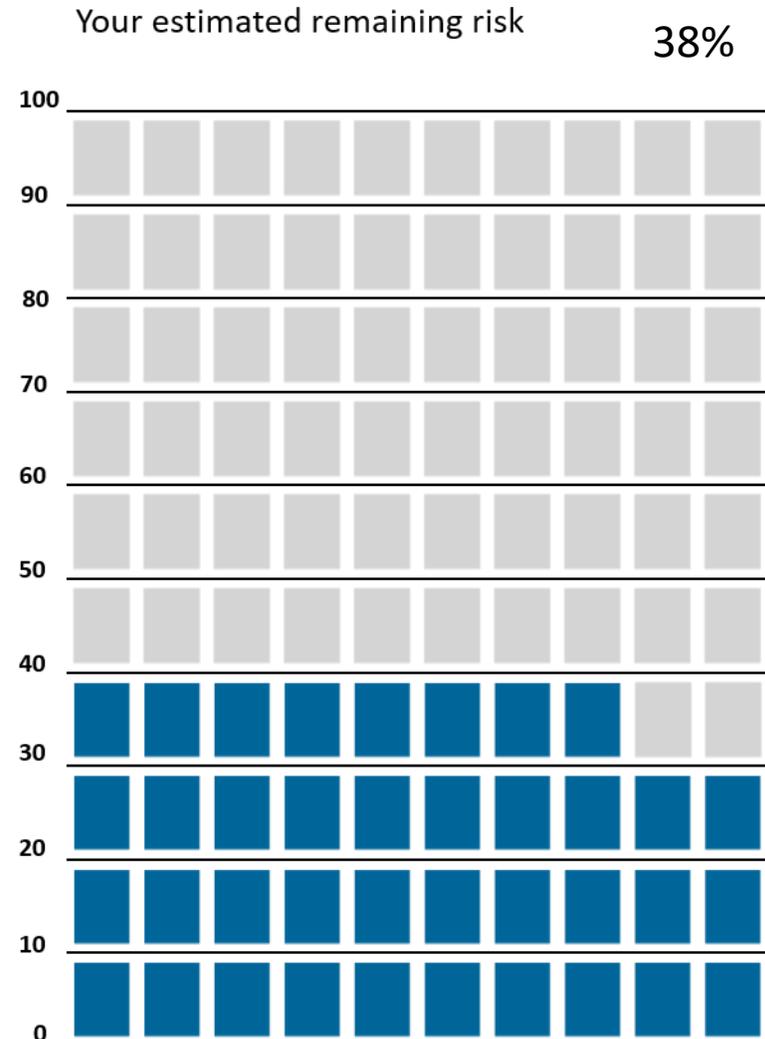
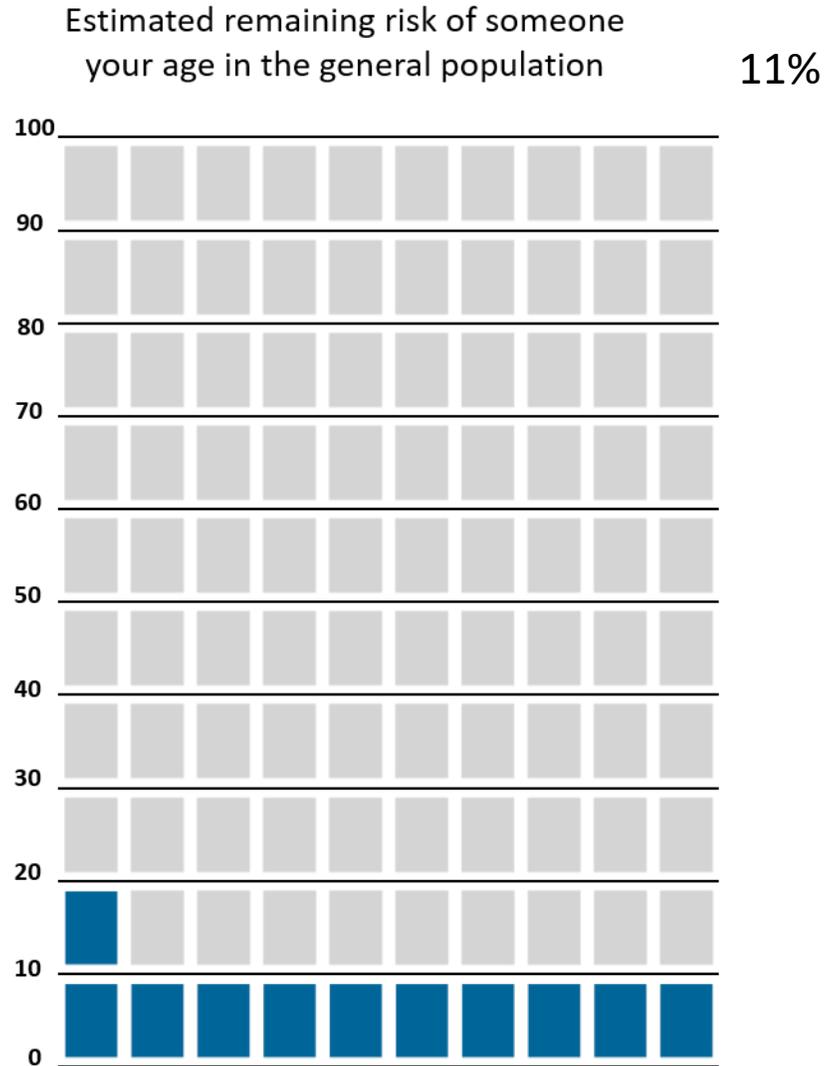
- Lifetime risk = risk of Alzheimer's disease dementia from **birth** to **death**.
- Remaining risk = risk of Alzheimer's disease dementia from your **current age** to age 85.
- In this study we will only disclose your remaining risk estimate.

Your estimated remaining risk of developing Alzheimer's disease dementia by age 85:

38%

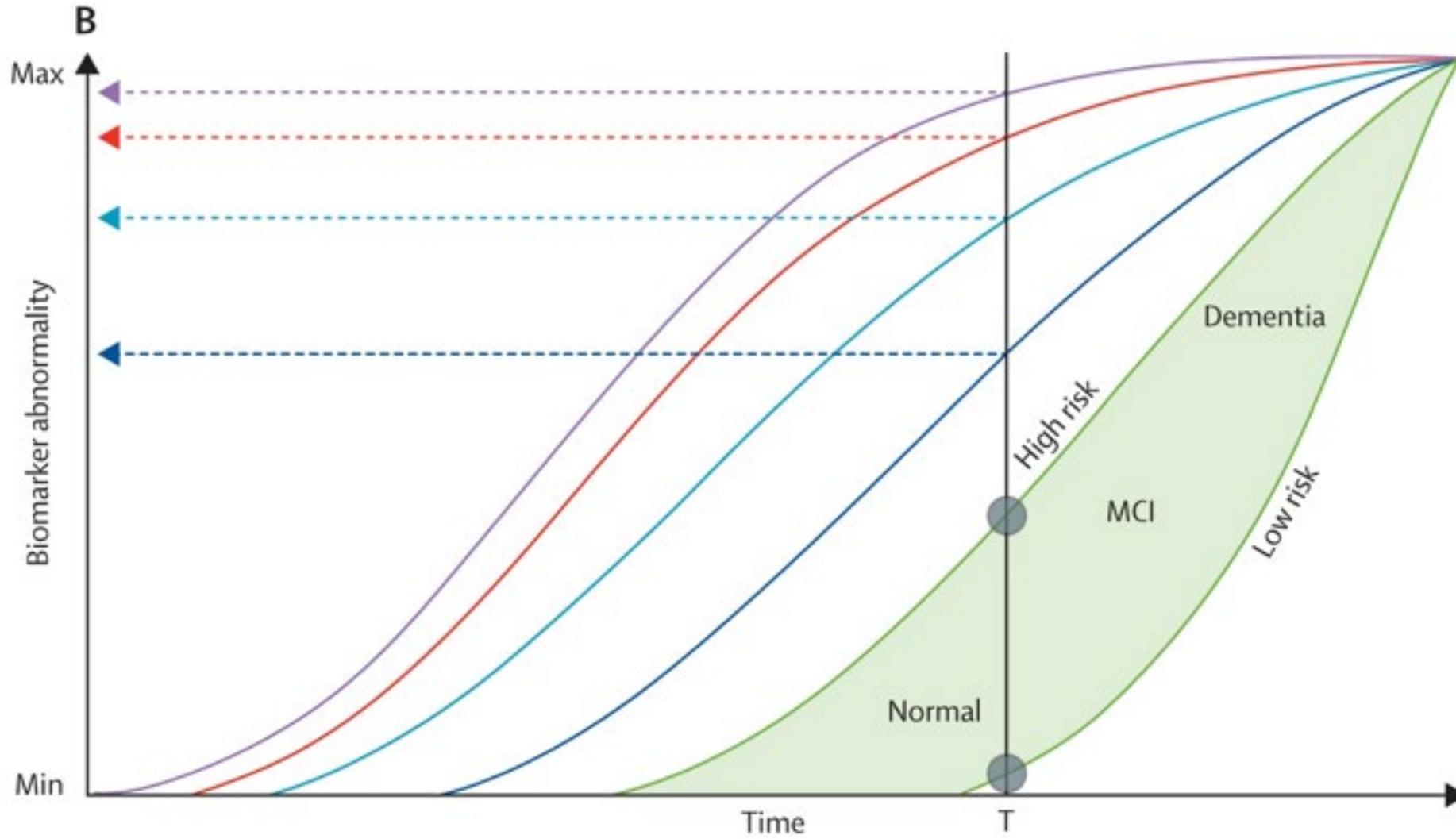


Comparing your estimated remaining risk to the general population

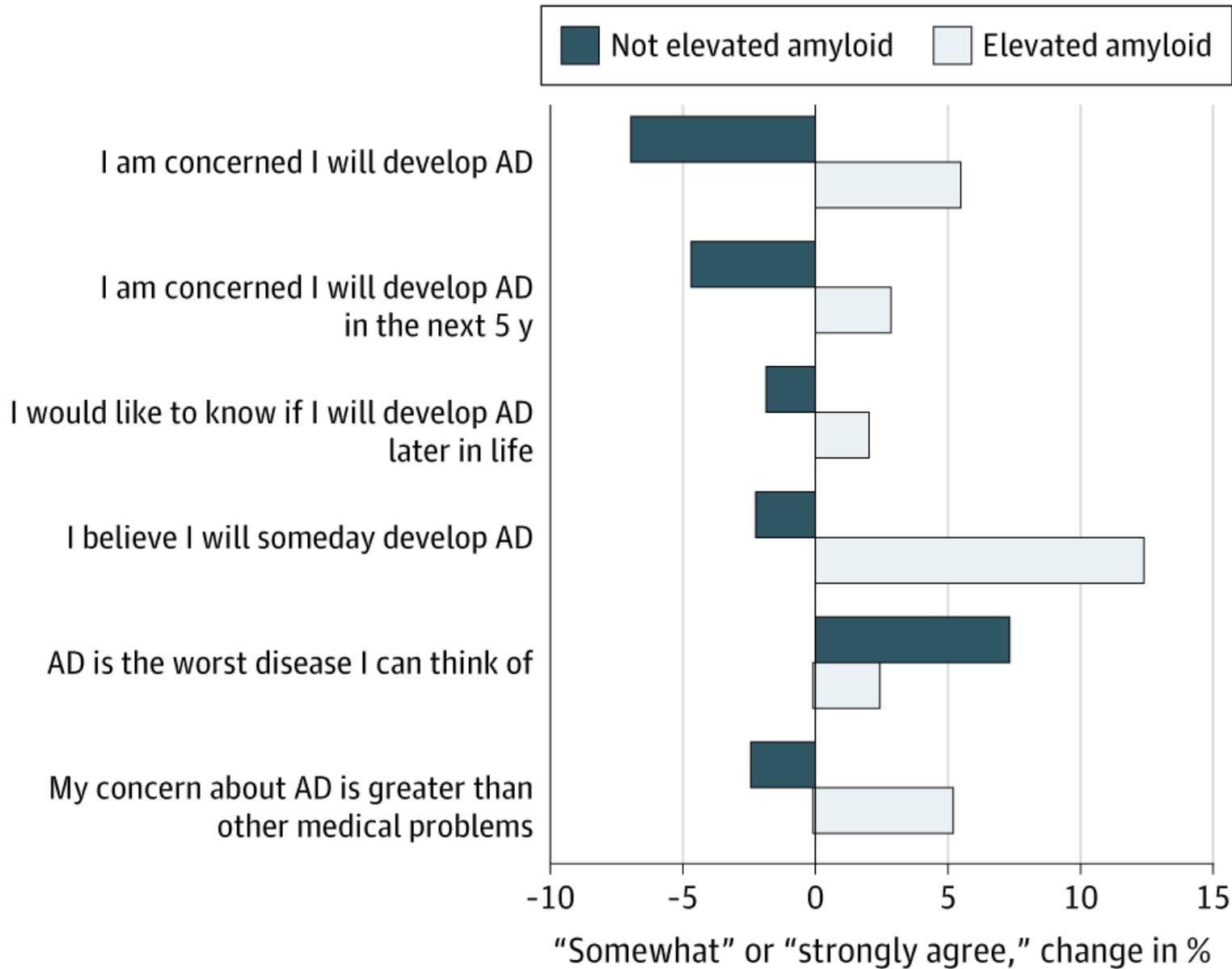


After learning “elevated amyloid” comes a feeling of limited remaining time

68 year old female, elevated amyloid: **I feel a little more that the clock is ticking than I did before.** Before I had the results, before I even thought about going in for the study, I was thinking I'll probably live to eighty, eight-five. Maybe I will. In the last ten years are like my mother's, I don't want to live that long. Yeah, again, it's changed my perspective on what I want to do with the time that I have left. Part of me says, "Okay. I want to enjoy myself more. I'm going to cut back on working even though that would be mean less income of course." Working is stimulating for me, and it keeps me going. I don't know. I'm conflicted. Yes. **I'm a little more conflicted about how I want to spend my time based on the fact that I may have limited time left."**



Jack CR, Knopman DS, Jagust WJ, et al. Tracking pathophysiological processes in Alzheimer's disease: an updated hypothetical model of dynamic biomarkers. *The Lancet Neurology*. 2013;12(2):207-216. doi:[10.1016/S1474-4422\(12\)70291-0](https://doi.org/10.1016/S1474-4422(12)70291-0)



Grill J et al. Short-Term Psychological Outcomes of Disclosing Amyloid Imaging Results to Research Patients Who Do Not have Cognitive Impairment JAMA Neurol Aug 2020.

Future Planning: Changes contemplated/enacted

	Elevated (50 total, 24 change)	Not Elevated (30 total, 5 change)	Not Elevated CF (28 total, 24 change)
Housing, Location, & Cohabitants	9	2	10
Financial Planning	9	0	3
Leisure Time & Activities	7	1	8
Planning (general, medical, legal)	5	0	8
Employment	2	1	2
Health Behavior	3	1	3
Activities of Daily Living	3	0	0
Assisted Suicide	2	0	0
Miscellaneous	0	0	2
Burden (reason for change)	6	0	4

*Not mutually exclusive. Responses were coded for as many changes as participant listed

LEARNING BIOMARKER RESULTS AFFECTS FAMILY MEMBERS.

'ELEVATED' AMYLOID- β

'NOT ELEVATED' AMYLOID- β



EMOTIONAL REACTIONS

“

[I]t's sad for me, and it was sad for him.”

“

[H]e ... seemed relieved. And I was relieved. ... We were happy.”



MEMORY

“

It just makes me a little more aware of [mom's] memory, just watching that in the back of my mind a little bit more.”

“

[I]f some memory lapse occurs, we say, 'This is [the] normal aging process. This isn't Alzheimer's.'”



HEALTH BEHAVIORS

“

[I]f I'm in better health, I [have a] better chance of being able to help her if she needs it.”

“

We still say that, hey we both have to do this [brain exercise] just in case.”



FUTURE PLANS

“

Maybe [we're] a little more mindful like, 'Okay, this isn't something we can put off for another 10 years.' [O]ur timeline has been pushed up.”

“

Since learning his [AD dementia risk] ... we feel freer to make plans.”

Challenges and Opportunities in Population Care: Medical Treatment and Long-Term Care

Meghan M. Skira
University of Georgia

CAPRA & NBER Conference
October 2022

Long-Term Care Overview

- Well-established that older adults prefer care in non-institutional settings.
- Usually begins in home- and community-based settings → skilled nursing facilities (SNFs) as disease progresses and advanced medical care is needed.
- Home- and community-based care
 - ▶ ~65% of older adults w/ ADRD live in the community (vs. ~98% w/out).
 - ▶ Settings: Home, adult day service centers, continuing care retirement communities (CCRCs), assisted living facilities
 - ▶ Care providers: Family caregivers, home health aides, skilled nurses, personal care attendants
- Skilled nursing facilities (SNFs)
 - ▶ ~50% of SNF residents have ADRD.
 - ▶ ~70% of those w/ ADRD die in a SNF.

Paying for Long-Term Care

- Medicare: Only if skilled services or rehabilitative care required.
 - ▶ SNF: Max 100 days
 - ▶ Home health: Only if required intermittently and under plan of care of a doctor.
 - ▶ Does *not* pay for non-skilled assistance w/ ADLs or IADLs.
- Medicaid: Must meet minimum state eligibility requirements.
 - ▶ Income/assets must be below certain level.
 - ▶ Some states extend eligibility to those requiring certain level of care.
 - ▶ Covers SNF care and some home- and community-based services.
- Long-term care insurance (LTCI)
 - ▶ Wide variation in services covered.
 - ▶ ~10% of those age 62+ hold LTCI.
- Out-of-pocket/personal resources

Medicaid Home- and Community-Based Services (HCBS)

- Medicaid state plan benefits: Provided to beneficiaries for whom they are medically necessary.
 - ▶ Home health services (required), personal care services (optional), Community First Choice attendant services/supports (optional), Section 1915(i) (optional)
 - ▶ Section 1915(i): HCBS targeted to particular population w/ functional needs *less than* institutional level of care.
 - Medical equipment, home accessibility adaptations, transportation, hospice care, respite care, home-delivered meals, adult day services, assisted living, skilled nursing, community transition services, case management
- Section 1915(c) HCBS waivers and 1115 demonstration waivers
 - ▶ Allow states to tailor HCBS to specific populations that meet SNF-level of care.
 - ▶ Enrollment caps and other cost containment measures permitted.
 - ▶ Often long waiting lists.

Medicaid Home- and Community-Based Services (HCBS)

Areas for Further Research

- Collect current and historical information about state plans and waivers.
- Which bundles of HCBS are effective in allowing those with ADRD to remain in the community?
- Complementarity and substitutability among HCBS as well as HCBS + family care.
- Recent increase in self-direction of HCBS, which allows individuals/families to determine the mix of services/supports that works best for them.
 - ▶ Given complexity of care for those w/ ADRD, what are best practices?

Skilled Nursing Facilities (SNFs)

- Serve 2 populations requiring different types of care:
 - ▶ Post-acute care: Short-term skilled nursing/rehabilitation after a hospital stay; Medicare dominant payer.
 - ~37% of short-stay residents have ADRD.
 - ▶ Long-term care: Services for those who can no longer reside independently in the community; Medicaid dominant payer.
 - ~60% of long-stay residents have ADRD.
- ~14% of SNFs have ADRD special care units (ASCUs).
 - ▶ Dedicated unit/wing/floor w/ services tailored to those w/ ADRD.
- Quality of care has been a long-standing concern; esp. during the pandemic.
 - ▶ Approaches to improve quality: Regulation, inspection, public reporting, P4P
 - ▶ Staff turnover esp. problematic.
- Recent evidence on selective admissions and discharges (Hackmann et al. 2021; Gandhi 2020).

Skilled Nursing Facilities (SNFs)

Areas for Further Research

- Effects of specialization (esp. ASCUs) on patient outcomes and spending.
- Peer effects/social interactions
 - ▶ Among residents in shared rooms (exploit variation in discharge incentives)
 - ▶ Among residents in ASCUs; spillovers to non-ASCU residents
- Modeling SNF choice
 - ▶ What does search process look like? Characteristics valued by family vs. resident?
 - ▶ Challenge: Choice set is never observed
- Addressing turnover; apply AKM models (who are the high-paying SNFs)
- Impacts of selective admissions/discharges on those w/ ADRD.
- Improving safety/resilience of SNFs against future infection outbreaks.

Medical Treatment

- Currently, 6 FDA-approved treatments for ADRD.
 - ▶ 5 treat ADRD symptoms but do not impact the underlying brain changes or disease progression; increase neurotransmitters.
 - ▶ FDA approved new drug, Aduhelm, in June 2021.
 - Reduces amyloid plaques; little evidence of improvement in cognition/functioning.
- Antipsychotics sometimes prescribed (off-label) to treat severe hallucinations, aggression, agitation in those w/ ADRD.
 - ▶ Linked to increased risk of stroke/death among those w/ ADRD.
 - ▶ Carry black box warning explaining these risks.
 - ▶ Prescribing factors into Nursing Home Compare 5-Star Quality Rating.

Medical Treatment

Areas for Further Research

- Role of physician detailing in prescribing of FDA-approved treatments for ADRD as well as off-label prescribing of antipsychotics.
- Document extent of geographic variation in treatment. Are there important differences in provider practice styles?
 - ▶ Do recent findings in the adolescent mental health context (e.g., Cuddy & Currie 2020) extend to the ADRD context?

Thank you!

Family Care

- Systematic training for family caregivers is limited.
 - ▶ Only ~7% of family caregivers for older adults receive training (Burgdorf et al. 2019).
 - ▶ Some ad hoc training by individual health care providers/community agencies.
 - ▶ Many caregivers are willing to complete training; even more so when training is subsidized (Cronin & Lieber 2022).
- Van Houtven et al. (2019): RCT that provided training to family caregivers of military veterans.
 - ▶ Training increased experienced quality of care.
 - ▶ Lacked power to analyze effects on veterans' subsequent use of health care.

Family Care

Areas for Further Research

- Design of family caregiver training, esp. for those w/ ADRD.
 - ▶ Requires granular understanding of tasks performed by family caregivers. How does ADRD care differ from other types of family care?
 - Also important for targeting caregiver supports.
- Effects of family caregiver training on care recipients and caregivers.