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The Bulletin on the Economics of Alzheimer's Disease and Related Dementias

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In This Issue

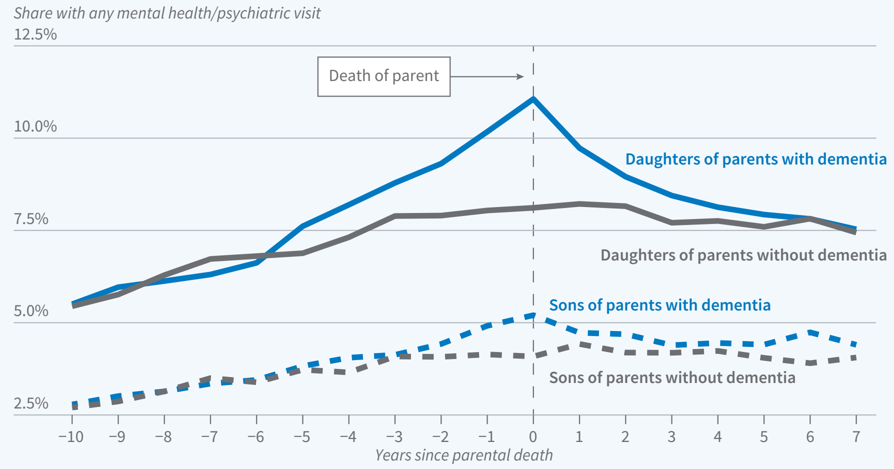
Parental Dementia and the Wellbeing of Adult Children

Alzheimer's disease and related dementias (ADRD) currently affect nearly 50 million people worldwide. This number is expected to grow substantially in coming decades. While direct medical expenses of ADRD are well documented, the full societal burden includes a variety of impacts on family members. Standard cost estimates typically capture only foregone wages from hands-on caregiving, overlooking broader effects on relatives' wellbeing, including mental health consequences, that may persist for years.

In Family Spillovers of Dementia (NBER Working Paper 34635), Onur Altındağ, Jane Greve, and Yulya Truskinovsky examine how parental dementia affects adult children's labor market outcomes, physical health, and mental health. Using population-wide administrative data from Denmark spanning the period from 1995 to 2018, they identify all individuals who died with an ADRD diagnosis between 2005 and 2011 and link them to their adult children, resulting in a sample of 36,112 children whose parent died with dementia. Each adult child is matched to a demographically similar individual whose parent neither had ADRD nor died in the same year. The researchers track outcomes in the 10 years before and seven years after the parent's death.

The researchers do not find any meaningful differences in labor supply, earnings, or physical healthcare use between the children of parents with ADRD and the control group. In contrast, mental healthcare use is substantially greater, particularly among women who have parents with dementia. Mental health–related visits among these women begin diverging from the control group approximately five years before a parent's death. Four to five years before a parent dies from ADRD, their daughters are 0.77 percentage points more likely to have a mental health visit, representing a 10 percent increase relative to the baseline rate of 7.7 percent. This rises to 1.12 percentage points (14.6 percent) two to three years before death and peaks at 2.17 percentage points (28.3 percent) during the three-year window surrounding the parent's death. Psychiatric medication use follows a similar pattern, increasing by 0.65 percentage points (3.8 percent) four to five years before death and reaching 1.27 percentage points (7.4 percent) around the time of death. This reflects greater use of antidepressants, anxiolytics, and hypnotics rather than antipsychotics. Effects are concentrated among women who lose a parent before age 50 and those with a college education, though effects appear across all education levels.

Mental Health of Adult Children of Parents with Dementia



In the study sample, adult children are those aged 35 and older.
Source: Researchers' calculations using Danish administrative registry data.

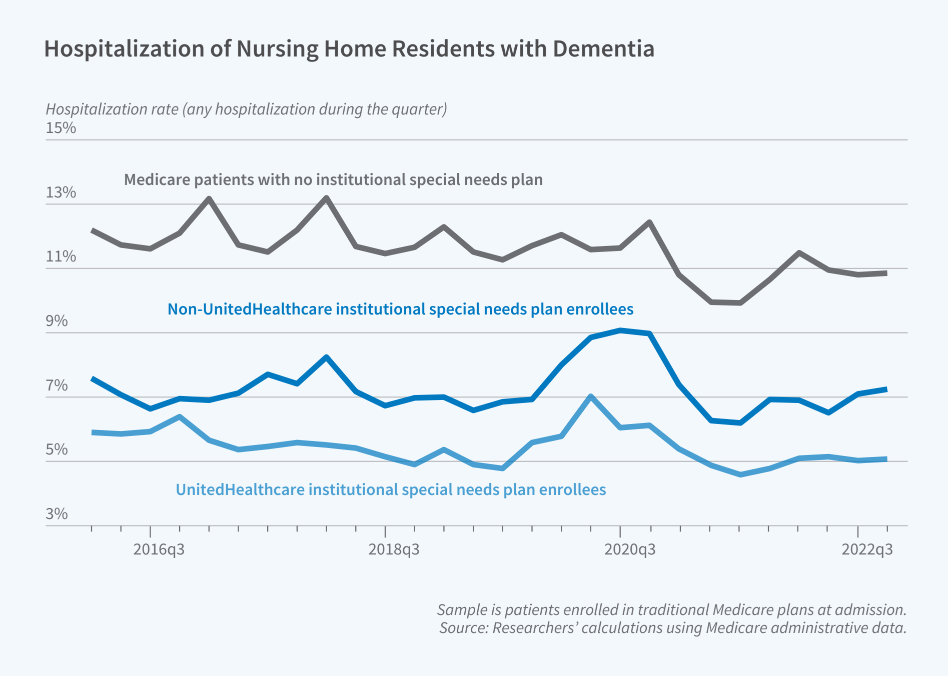
For men, whose baseline mental healthcare use is substantially lower, effects are more muted and concentrated around the year of parental death. Mental health visits increase by 0.66 percentage points (16.7 percent) and psychiatric prescriptions by 0.67 percentage points (6.6 percent) during the three-year period surrounding death, with some evidence of persistence for up to seven years after the parent's death.

The researchers compare their findings with those from a larger sample of 195,687 individuals whose parents died without ADRD. Parental death from non-ADRD causes produces sharp but short-lived increases in mental healthcare use concentrated around the year of death, contrasting with the decade-long elevation observed for ADRD-related deaths.

The researchers acknowledge seed funding from the Hopkins Economics of Alzheimer's Disease & Services Center and the Bentley University Research Council, and full funding from the Independent Research Fund Denmark.

Institutional Special Needs Plans for Nursing Home Residents with Dementia

At any given time, nearly 1 million Americans reside in a nursing home and receive long-term care, with most having some form of dementia. Nursing homes operate under fragmented financing where Medicare pays for post-acute care only after a three-day hospitalization, while Medicaid or private payments cover long-term care. This system discourages investment in on-site clinical capabilities and encourages facilities to transfer residents to hospitals for treatment of acute illnesses. In 2022, post-acute care margins for nursing homes were 22 percent compared to an overall margin of –1.3 percent across all payers, creating strong financial incentives to hospitalize residents to access higher Medicare payments. Consistent with these incentives, these facilities face persistently high hospitalization rates.



Hospitalization of Nursing Home Residents with Dementia

Sample is patients enrolled in traditional Medicare plans at admission.
Source: Researchers' calculations using Medicare administrative data.

Enrollment in Institutional Special Needs Plans reduces quarterly hospitalization rates by about 3 to 4 percentage points among long-stay nursing home residents with dementia.

In Is Managed Care Effective in Long-Term Care Settings? Evidence from Medicare Institutional Special Needs Plans (NBER Working Paper 34235), Momotazur Rahman, Brian McGarry, Elizabeth M. White, David C. Grabowski, and Cyrus M. Kosar examine whether Institutional Special Needs Plans (I-SNPs) can reduce hospitalizations while maintaining care quality. I-SNPs are Medicare Advantage plans designed exclusively for individuals certified as requiring facility-based long-term care. Unlike traditional Medicare, I-SNPs receive capitated payments and eliminate the three-day hospitalization requirement for post-acute care coverage, creating incentives to reduce costly hospital use. Additionally, I-SNPs must operate a Medicare-approved clinical model of care which includes employing advanced practice clinicians who work on-site in nursing homes to coordinate care and treat acute illnesses in place. The share of long-stay nursing home residents enrolled in I-SNPs quadrupled between 2006 and 2021, from 2.2 percent to 8.8 percent. The largest and oldest I-SNP is operated by UnitedHealthcare (UHC), but more recent growth has been driven by non-UHC plans.

The researchers analyzed 12 million resident-quarter observations from 2016 through 2022. They examined long-stay nursing home residents aged 65 and older with Alzheimer's disease and related dementias and compared outcomes for residents before and after their facility began offering I-SNPs. When I-SNPs were offered, individual enrollment increased by approximately 20 percentage points. For residents who entered a nursing home with conventional Medicare Advantage coverage, I-SNP enrollment decreased hospitalization by approximately 3 percentage points. Among residents who entered nursing homes enrolled in traditional Medicare, I-SNP enrollment reduced quarterly hospitalization rates by roughly 4.3 percentage points.

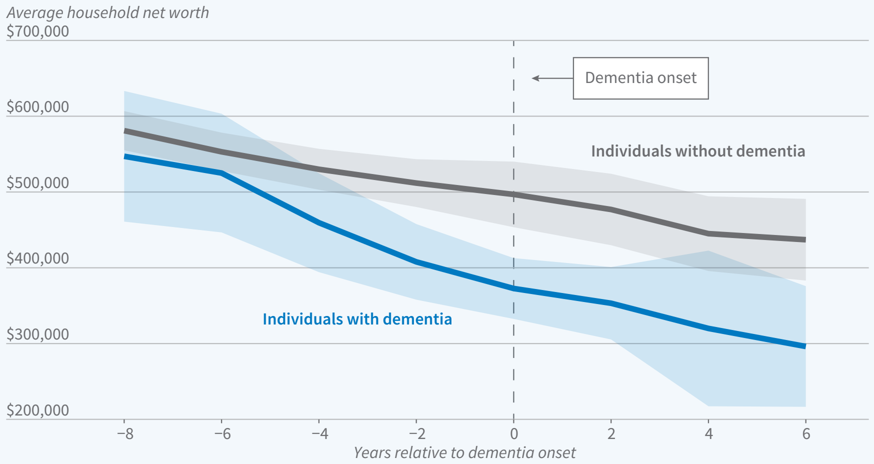
For UnitedHealthcare I-SNPs, the probability of hospitalization fell by between 3.5 and 4.1 percentage points for Medicare Advantage entrants and by around 4.5 percentage points for traditional Medicare entrants. Non-UHC I-SNP enrollment yielded smaller effects of around 2 percentage points for Medicare Advantage entrants and between 3.0 and 3.6 percentage points for traditional Medicare entrants. Using a hospitalization measure based on nursing home discharge assessments, the researchers find that I-SNP enrollment reduced the probability of discharge to any inpatient facility by roughly 2.9 percentage points and 4.3 percentage points for residents originally enrolled in conventional Medicare Advantage plans and traditional Medicare, respectively. The magnitude of the hospitalization reductions increased the longer an I-SNP was present within a nursing home, indicating growing effectiveness as partnerships between plans and nursing homes developed.

The researchers did not find any evidence that I-SNP enrollment raised the risk of adverse secondary outcomes. Using baseline hospitalization rates and average Medicare hospitalization costs, the researchers estimate that approximately 80,000 hospitalizations out of 240,000 could have been avoided with I-SNP enrollment, translating to $1.2 billion in savings for Medicare.

The researchers acknowledge support from the National Institutes of Health's National Institute on Aging grants R01AG082098 and R01AG089051.

The Financial Impact of Cognitive Decline Before Dementia Diagnosis

Dementia and Trajectory of Household Net Worth



Shaded area represents 95% confidence intervals.
Source: Researchers' calculations using data from the longitudinal Health and Retirement Study.

Household wealth begins declining approximately six years before dementia onset, primarily through impaired management of liquid financial assets.

Dementia imposes substantial costs on individuals and society through healthcare expenses and caregiving needs. However, the economic consequences may begin years before clinical diagnosis, as cognitive decline can impair financial decision-making, compromise portfolio management, and increase susceptibility to fraud. In Dementia and Long-Run Trajectories in Household Finances (NBER Working Paper 34659), Jing Li, Kathleen M. McGarry, Lauren Hersch Nicholas, and Jonathan S. Skinner use nearly two decades of data from the Health and Retirement Study (HRS) to compare the financial trajectories of individuals who eventually develop dementia with those of similar individuals who do not.

The researchers classify individuals as having dementia when their predicted dementia probability exceeds 50 percent, capturing cognitive impairment regardless of clinical diagnosis timing. The study includes 2,312 individuals who are classified as having dementia, and 8,431 controls who are not so classified. The sample households are observed between 2000 and 2016.

The researchers estimate that wealth divergence between those who develop dementia and those who do not begins approximately six years before dementia onset. The gap in mean household net worth between the two groups widens roughly four-fold during this period, from about $30,000 before divergence to nearly $125,000 at dementia onset, with financial wealth and non-financial wealth accounting for roughly two-thirds and one-third of the gap, respectively. The relative decline in financial wealth is most pronounced between six and four years before onset, while the relative decline in non-financial wealth accelerates closer to onset.

Neither reduced earnings nor higher healthcare spending can explain the magnitude of the wealth gap. The differential earnings decline at dementia onset is less than $1,000. Out-of-pocket healthcare spending among those with dementia exceeds that of controls by about $1,000 to $1,600 per year in the years before onset, far too small to explain the wealth decline. The study finds no evidence of increased total household spending before dementia onset, contradicting explanations based on intentional "spend-down" to qualify for Medicaid nursing home coverage. Respondents show no awareness of an elevated risk of needing long-term nursing home care even though the likelihood of residing in a nursing home is 17 percentage points higher for those with dementia at onset than for the control sample.

The researchers conclude that impaired financial decision-making is the most likely source of the diverging financial trajectories between those with and without dementia. The largest wealth declines occur in liquid assets requiring active management, particularly stocks, bonds, mutual funds, and investment accounts, while checking and savings accounts show smaller but meaningful relative declines. In contrast, more restrictive retirement accounts show no relative change, likely reflecting the fact that accounts requiring less active management are more insulated from the effects of cognitive decline.

Individuals receiving timely memory-related diagnoses experience some wealth recovery after onset, particularly in financial assets, while those with late or no diagnosis continue losing wealth. Importantly, individuals with other serious medical conditions like cancer or heart disease show no similar pre-onset wealth declines, suggesting these patterns are specific to cognitive impairment.

The researchers acknowledge support from the National Institute on Aging of the National Institutes of Health grants K01AG066946 and R01AG069922.

Q&A with Professor Kathleen McGarry, Co-Principal Investigator of the NBER Coordinating Center on the Economics of Alzheimer's Disease and Alzheimer's Disease-Related Dementias (AD/ADRD) Prevention, Treatment, and Care

Introduction

Kathleen McGarry is professor and chair of the Department of Economics at the University of California, Los Angeles where she has been since 1992. She is a co-principal investigator of the NBER Coordinating Center on the Economics of Alzheimer's Disease and Alzheimer's Disease-Related Dementias (AD/ADRD) Prevention, Treatment, and Care. She also leads the NBER International Long-Term Care project. McGarry is also a co-investigator of the Health and Retirement Study and served as a senior economist at the White House Council of Economic Advisers over the period 2000–01.

Research Background and Expertise

Question: What initially drew you down the path of studying the economics of long-term care generally?

McGarry: My research has always focused on the economics of aging. I began studying poverty among the elderly as a graduate student, and that quickly led to research on public transfers like the Supplemental Security Income program, Social Security, and then eventually to family transfers. And in the United States, transfers between family members tend to go—what they term—downstream from parents to children with parents making inter vivos transfers to the children while they're alive and bequests after they die. Children also give to elderly parents, but here the mechanism tends to be in terms of time help with children taking care of their elderly parents by providing long-term care or other types of help. So, I just sort of transitioned into working on that topic, looking at how individuals insure against long-term care, the role of families (and particularly the role of daughters) in caring for their elderly parents.

I think one of the striking aspects of our long-term care system is the lack of insurance coverage. Medicare covers healthcare for the elderly but doesn't really cover long-term care. Medicaid does cover long-term care, but only for those who have little in the way of financial resources. Despite this gap in insurance coverage, and probably in part because people don't realize there is a gap, the market for formal long-term care insurance is very small and families end up shouldering the burden of providing care. That places a lot of stress on families, and particularly in the case of a parent with dementia, where patients often need around-the-clock care, that's exhausting, stressful work, and it has negative financial and health consequences for the caregiver. So I started doing a lot of research on that issue.

I think one of the things that's so interesting is it's not just a US problem, but something that countries around the world face, both developed and developing nations, and countries with national long-term care insurance programs, and without, and nobody really has a good answer. So, it's interesting to study a question that we haven't figured out the answer to. I think the second aspect of the subject that interests me is that it's such a personal topic for many. Whenever I give a talk on long-term care anywhere, people come and tell me their stories about their own families, their grandparents, their parents, how it's touched them. And it's nice to feel like I'm studying something that matters.

Question: Could you briefly summarize the most significant or perhaps surprising findings from your research on this topic?

McGarry: This is an international problem. Four years ago, Jon Gruber and I started the NBER International Long-Term Care project, which tries to learn something by looking at how long-term care is provided around the world. We started with a group of 10 countries and released a first volume through the NBER and the University of Chicago Press. One of the really interesting things that we learned in looking at the landscape for long-term care in all these countries is no matter what sort of system is in place, whether there's national long-term care insurance, like in Germany, or extensive coverage through national health insurance programs or means-tested programs, like in the US or England, families end up providing much of the care. So even though we don't have a national long-term care insurance program while other countries do, they still have families shouldering much of the burden.

The second point related to this idea is that, even in countries without national long-term care insurance like the US, the public sector ends up paying for much of the formal care. In the US, many people eventually become eligible for Medicaid and that program ends up covering much of their care. So even though very different institutional infrastructures exist, a lot of the outcomes end up being the same. That, to me, was really surprising. We tend to think in the US, oh, we got it all wrong, everybody else knows what they're doing. And it's not really true.

Question: What role can economic research play in improving the quality of life for those with dementia and their caregivers?

McGarry: I think a big role that we can play is providing a better understanding of the risks and the costs of long-term care. We can help individuals and their families prepare for potential future needs. One of the things we're learning about is that the impact of dementia and cognitive decline generally starts very early, far before any sort of formal medical diagnosis. There have been some recent economic studies that show that individuals who are eventually diagnosed with dementia are significantly more likely to make financial mistakes, like missing payments on a credit card or having their credit score go to subprime, as early as six years before diagnosis.

Another recent paper found significantly larger declines in wealth among those who develop dementia relative to those who don't, again, about six years before diagnosis. So wealth starts declining, whether it's due to financial mistakes or fraud or whatever is happening. Economists also show, in another paper, that individuals fail to recognize early declines in cognition. In the Health and Retirement Study, individuals are asked if their cognition has declined and they say, no, it's the same as or better than it was when you interviewed me a couple of years ago. And yet you can look in their responses to cognitive tests and see that it's declining. So we don't realize that we're having problems and we're making mistakes. I think if people were aware of this, they could make better plans, setting up, sort of, checks and balances in their financial life, perhaps having a child or advisor or someone help with their finances, or just keep an eye on things. I think it's important to realize that you're not going to be able to be aware of your own decline.

I think the other thing we need to make people aware of is that there's a very real chance that they're going to need formal care someday, whether at home or in an institution. And particularly in the case of dementia, as we talked about earlier, families can't do this and that level of care is expensive. So planning is important. Economists can, I believe, contribute just by highlighting the need to plan for these contingencies and by helping to improve the functioning of long-term care insurance markets. Many economists have studied long-term care insurance, myself included, and people are now looking at substitutes like the role for home equity in financing care, or new financial products like joint life insurance and long-term care insurance products.

And when we think of costs, we need to realize the costs are not just the price of a caregiver or the nursing home, but also the costs borne by family. They may have to take time out of the labor market and reduce hours of work. One of the things I found was slower wage growth among caregivers. You can't take on that extra project at work. You can't stay overtime or maybe travel for a business trip or something similar because you have caregiving responsibilities. So it ends up affecting your career path. There are also studies showing that caregiving impacts the health of the caregiver with increased levels of stress and declines in self-reported health. If we knew this ahead of time, we might be able to plan better and understand what's going to happen. At least be aware of it, maybe save more early on in your career because you know you might have to take time off to care for a parent or something like that. And also help with public policies to try to protect caregivers, to try to help with insurance, and those sorts of things.

Question: What do you see as the greatest challenges as we move forward with a growing aging population?

McGarry: I think that's it—the sheer increase in the number of elderly people that we're going to have to care for and the growing number with long-term care needs. As you know, people are living longer, but there are also declines in fertility, making it increasingly difficult to find caregivers. Part of the aging of the population is that coming generations of elderly are going to have fewer children. Right now, the baby boomers are providing care for their elderly parents. Soon they're going to be the ones needing care and they have fewer children to provide that care or to take on any sort of financial responsibility for paying for that care.

In the formal sector, we're already dealing with shortages of paid caregivers, and that situation is going to be exacerbated over time. We just talked about what a difficult job caregiving is; it is a low-wage job with difficult working conditions. People aren't flocking to it, especially after the COVID pandemic. Lots of people are leaving the industry. So, we need to find ways to attract more people to this type of employment, which is going to require better wages and better working conditions. I think that's where we'll really struggle.

About the NBER Coordinating Center

Question: Can you explain the mission and goals of the NBER Coordinating Center on the Economics of Alzheimer's Disease and Alzheimer's Disease-Related Dementias (AD/ADRD) Prevention, Treatment, and Care?

McGarry: The Center obviously aims to foster economic research and encourage more economists to address these many outstanding questions and develop new avenues of research. There are interesting topics in the space, regardless of the field in economics in which one wants to work. Health economics is obviously relevant, and there are the labor economic issues I've talked about in terms of the employment effects for caregivers and attracting workers to the profession. But also understanding the role of technology. Can we use technology to help with the demand for caregivers? Stepping outside of the most obvious topics, there are important questions in fields like industrial organization: What's the ideal structure of nursing homes and the home healthcare industry? In developing economies, we need to examine care in those countries where children have left rural areas and moved to cities or moved to other countries. How are they going to care for their elderly? And, of course, modeling options for optimal insurance design.

Interestingly, one of the projects supported by the Center looks at the relationship between lead water pipes in the last century and later dementia. So, economic historians are involved. It's hard to find a field in economics that cannot contribute to understanding and addressing some of these issues. Economists really need to start realizing that the type of work they're doing, regardless of field, can answer or help answer some of these important questions. Therefore, one of the Center's goals is to highlight the topic, and the questions, and try to attract more people to work on them.

Question: The Center is prioritizing some topics of research. Could you expand upon some of the most important ones?

McGarry: I think all the principal investigators have their favorite topics. I'll just go back to what I have said. There are so many important issues. I wouldn't want to say one's more important than others, and I'm sure there are topics we haven't thought of. I never would have thought to start a project looking at lead in water in the last century and what that means for dementia today. So, there are going to be things we haven't even thought of that are important to understanding the economics of dementia. I would encourage researchers just to think creatively about the work they're doing, what ties there might be, and to propose ideas. I hate to equivocate so much, but everything is going to be important.

Question: What opportunities exist for junior researchers to get involved in the Center that might bring some of these ideas?

McGarry: It's a great opportunity for junior researchers; they are setting up their career path and realizing that the economics of Alzheimer's, dementia, and long-term care has important questions. Specifically, we have awards we call "EC-READs" for early career research in the economics of ADRD. These are two-year awards that include funding but, importantly, also have a mentoring component. That's unusual for many grants. The recipient not only receives funds they need to carry out their work, but they're paired with a senior researcher in the field who serves as a mentor. In addition, they're invited to training sessions that the NBER runs. We just held one discussing topics like submitting research papers to journals, responding to referee reports, and so forth. And through the EC-READ awards, early career researchers are given opportunities to present at both smaller Center events and larger public conferences.

I want to encourage junior researchers to think about the other opportunities that come with being part of the consortium through an early career grant and think about applying for it because of these valuable mentorship opportunities. You become part of a group of people and you're going to get lots of support and advice.

Question: What would success look like for the Center five years from now?

McGarry: We hope to foster a large and growing group of affiliated scholars who've used their research awards to launch their careers in new directions, and to have been successful in attracting new people to the field. The economics profession is full of extremely intelligent and creative scholars working in a variety of fields and having more people turn some of their attention to understanding the economic aspects of dementia and long-term care can really move this research forward. I also hope that as we get more existing scholars working on this topic, a snowball effect emerges where they will also train their graduate students in the area, and we'll witness a new generation of researchers in ADRD and related topics. It's not something economists have paid a lot of attention to before, but given the growing need, the importance of policy, and the importance just on a personal level, I really hope we can get that message out and attract lots of people who never thought of this as a topic that their work could address.

Review of the 2025 Literature on the Economics of Alzheimer's Disease and Alzheimer's Disease-Related Dementias

This second annual targeted review of the literature on the economics of Alzheimer's disease and Alzheimer's disease-related dementias (AD/ADRD) consisted of 52 impactful articles from 2025. A searchable database of each article, including its key results, cohort information, and related Coordinating Center research priorities, can be found here.

This review contains articles on the major themes identified in the previous review (i.e., caregiving, cost of care, long-term services and supports, healthcare and payment policy, health disparities) in addition to a new theme focused on economic evaluations of anti-dementia therapeutics. Formal healthcare and payment policy was the most commonly discussed topic within the literature, centering on how various payment models impacted quality of care. The relationships between AD/ADRD severity and caregiving burden or cost of care were often examined. The impact of socioeconomic demographics on anti-AD medication access, end-of-life care, an individual's cognitive health, and broader dementia prevalence was explored across multiple themes.

Formal Healthcare Models and Payment Policy

Payment policies influence the access to and quality of formal care for patients with AD/ADRD, ultimately impacting their health outcomes.

Revised on May 18, 2026. This *Review of the 2025 Literature on the Economics of Alzheimer's Disease and Alzheimer's Disease Related Dementias* report was prepared by Rose Li and Associates, Inc. (RLA) under contract to the National Bureau of Economic Research (NBER) Coordinating Center on the Economics of AD/ADRD Prevention, Treatment, and Care (U54 AG090084). RLA associates who authored this document include Colette Li and Meghan Walsh. The views expressed in this document do not necessarily reflect those of the sponsoring agency.

Skilled nursing facilities (SNFs) and long-term care (LTC) facilities constitute a significant share of formal patient care. Yun et al. found that the quality of resident care improved (i.e., reduced emergency department visits or hospitalizations) when residents received care from a physician who practiced primarily in nursing homes.[1] Chen and Jang, exploring the relationship between self-report quality of care measures and care costs, found that higher self-reported quality of care was significantly associated with lower Medicare costs, especially for people living with dementia (PLWD).[2]

Accountable care organizations (ACOs) are a multidisciplinary coordinated care model that payers use to improve care quality. Wang et al. found that ACO-attributed Medicare beneficiaries were more likely to enter high-quality SNFs than those enrolled in traditional Medicare.[3] However, patients with AD/ADRD were less likely to enter high-quality SNFs regardless of payer status.[3] This disparity may be due to the higher costs associated with AD/ADRD care in conjunction with Medicare plans not incentivizing SNFs to care for this population.[3] Despite racial/ethnic minority populations having greater ACO-associated cost savings, patients who were White, did not have dual Medicare-Medicaid coverage, and lived in neighborhoods with low social vulnerability were more likely to receive care through ACOs.[4,5] Broadly, nursing homes with a higher proportion of Black or Hispanic residents were less likely to have AD special care units; however, this disparity was smaller in states with higher Medicaid payment-to-cost ratios.[6]

The US nursing home industry relies heavily on Medicaid financing.[7] In 2003, federal reform aimed to restrict states that were misallocating nursing home Medicaid funds. However, Indiana circumvented the reform by encouraging county hospitals to municipalize private nursing homes, which financially incentivized the hospital systems to increase the care volume (i.e., number of Medicaid days) provided. While no change in each nursing home's quality was observed following municipalization, the care volume increase was concentrated in the lowest-quality nursing homes, essentially expanding lower-quality nursing home care.[7] Payer policy also influences the ability of older adults to age in place. In one study, Cui et al. found that racial/ethnic minorities used telemedicine more often than other PLWD to assist with aging in place, implying that removing the increased access to telemedicine spurred by COVID-19 restricts access to high-quality home-based care for these vulnerable groups.[8] Living in rural areas can compound care accessibility issues. Thunell et al. found the availability of 1915(c) Medicaid waivers for paid family caregiving was associated with the likelihood of only receiving family care, and not any formal care, particularly for PLWD in rural areas.[9]

The type of Medicare plan held by a PLWD also impacts access to and type of care received. Medicare Advantage (MA) plans are incentivized to prioritize preventative care, as well as document all diagnoses to increase their risk-adjusted per-member-per-month payment, which would explain why older adults with MA, especially PLWD, were more likely to attend an Annual Wellness Visit than those with traditional Medicare (TM).[10] However, even though MA disenrollment rates decreased from 2010 to 2022, they still remained higher than disenrollment rates from TM.[11] When nursing homes started participating in an Institutional Special Needs Plan (I-SNP), their long-stay residents often switched from MA or TM to the I-SNP, which was associated with reduced hospitalization rates.[12]

Cost of Care

Accurately understanding the true costs and economic impact of dementia in the United States and around the world is vital to making decisions about policy, resource allocation, and research priorities. Gracner et al. found that the aggregate lifetime cognitive impairment burden for adults in the United States was $627 billion, with 41% attributable to mild cognitive impairment (MCI).[13] Tahimi Monfared et al. found that while the estimated societal cost burden of AD (including intangible costs to patients and caregivers, costs to businesses, costs of unpaid caregiving, and direct costs) was almost double those of MCI, although costs for MCI were still considerable.[14] One small retrospective study of electronic health records data found that patients with advanced AD had significantly higher AD-related healthcare resource utilization than those with early AD but not significantly higher all-cause healthcare resource utilization.[15]

International studies in Europe and Asia also found that costs increased with AD severity.[16,17,18] However, type of care costs may vary across disease progression. A German study found that patients with AD had lower costs for physician treatments and medical aids than those with MCI or subjective cognitive decline, despite overall higher formal and informal care costs, perhaps due to a shift in disease care complexity, lack of mobility, difficulty expressing symptoms, or increased reliance on informal caregiving.[16] When evaluating the economic burden of inpatient AD care in China's Hubei province, Chen et al. found that advanced age, commercial insurance, and comorbidities (i.e., infections, fractures, and cardiovascular disease) were associated with increased costs.[19] The average cost per patient with AD increased from 2014 to 2019 in Italy, with 87% of the total annual cost associated with hospital admissions.[20] Araya-Ríos et al. reported the first utility weights for the Alzheimer's Disease 5 Dimensions Instruments for use in the Chilean population, allowing for future estimates incorporating quality-adjusted life years.[21] The number of dementia-attributed disability-adjusted life years (DALYs) in the Minas Gerais state of Brazil derived from the AD/ADRD cases reported to the Brazilian Ministry of Health was lower than those found in the Global Burden of Disease Study, which indicates possible underreporting.[22]

Health Disparities

Multiple studies explored the relationship between socioeconomic factors and cognitive health. Cognitively impaired individuals, like those with AD/ADRD, often struggle to make cogent financial decisions and have resultantly poor financial performance.[23,24] Increased socioeconomic status (SES) was associated with a reduced risk of AD/ADRD.[25] SES may influence dementia risk through labor force participation. In the years prior to a young onset AD diagnosis, individuals in Denmark were more likely to be unemployed or use long-term sick leave than matched controls.[26] However, no clear relationships between paid employment or volunteering history and preclinical AD (i.e., no detectable MCI but some amyloid accumulation) were observed, although this may be due to amyloid levels being an inappropriate disease surrogate when assessing short-term economic outcomes.[27] In a study examining how stressful life events influence AD pathology and neurodegeneration in cognitively unimpaired individuals at high AD/ADRD risk, economic stressors (e.g., unemployment, financial loss) were related to gray matter volume loss, while grief-related stressors were related to AD pathophysiology (i.e., Aβ, p-tau, or neurogranin).[28] The neurodegenerative effects due to unemployment mainly affected men and those with higher education, while financial loss mostly affected women.[28]

Educational attainment is shown to have a protective effect relating to AD/ADRD risk and decline. Increased educational level was linked with reduced incidence and delayed onset of AD/ADRD,[29] and increased word recall in older adults.[30] Cao et al. found that 17% of the protective effect that education has on cognitive function later in life was due to reduced occupational hazard exposure (e.g., extremely bright or inadequate lighting, extreme temperatures) and not from increased cognitive complexity exposure.[31]

Caregiving

The financial burden of spouses, children, or friends caring for PLWD is a significant portion of the total costs associated with AD/ADRD. Vilaplana-Pireto and Oliva-Moreno found that each informal caregiver for a person with AD in Spain provided an average of 4,596 to 5,430 hours of care annually, which, when valued over the whole population, is larger than the entire budget for Spain's LTC system.[32] Caregivers from minority populations are disproportionately burdened. In the United States, the total estimated economic burden of AD/ADRD, mainly driven by unpaid caregiving, on African American and Latino adults was projected to increase to $1.7 trillion in 2060, larger than the projected $1.4 trillion cost on the larger White population.[33] This disproportionate burden is likely due to African American and Latino communities experiencing increased prevalence rates of AD/ADRD and associated comorbidities along with reduced access to high-quality health care.[33]

Similar to costs, caregiver burden is related to AD severity. Kraake et al. found that poorer social functioning, common in patients with more severe AD, was associated with increased caregiver burden, perhaps due to the patient's increasing dependence on the caregiver for assistance with activities of daily living and social interaction.[34] Close familial ties (e.g., parent, spouse) between the individual living with dementia and their caregiver was also found to be associated with increased caregiver burden.[35,36]

Caregivers of early AD and MCI reported a low financial impact of caregiving and had better quality-of-life scores than the caregivers of patients with advanced AD.[37,38,39] Despite increased burden being associated with more advanced disease stage, nonetheless, one study reported substantial burden associated with caring for individuals with MCI, regardless of whether the individual progressed to dementia.[39]

Long-term Services and Supports

Home and community-based services tailored for AD/ADRD care needs are required to enable older adults across the disease spectrum to continue living in their communities for as long as possible. Lenzen et al. used a discrete choice experiment survey to design a home-based occupational therapy dementia community program in Australia, finding that high value was placed in the program improving the patient's level of independence and dementia-related behavior.[40] Home health care utilization increased for PLWD from 2010 to 2020 and then decreased through 2022, perhaps due to home care agencies' staffing shortages during the COVID-19 pandemic.[41] Hanchate et al. found that following pandemic-related telemedicine expansion in March 2020, both telemedicine and home-based medical care (HBMC) visits increased. However, the HBMC visit increase was concentrated in regions with high HBMC provider availability by White PLWD and not Hispanic or Black PLWD.[42]

End-of-life care is an important consideration for all older adults but can be challenging to discuss with PLWD. Studies by Xie et al. and Gruber et al. found that PLWD who were ethnic/racial minorities, had lower SES, or lived in rural areas received less palliative care, despite palliative care use being associated with reduced costs.[43,44] For-profit hospice enrollment, rather than nonprofit hospice enrollment, was associated with an increased length of stay, as well as an increased likelihood to exceed the Medicare reimbursement cap, indicating that policies to limit marginal hospice use may be insufficient.[44]

PLWD are at a higher risk of being prescribed potentially inappropriate medication, which is predictably associated with higher healthcare resource utilization and total healthcare costs.[45] One study found nearly a third of patients with both AD/ADRD and insomnia were prescribed potentially inappropriate oral sedative hypnotics and atypical antipsychotics, a larger portion than the approximately 20% of patients with insomnia alone who were prescribed these medications.[45] Despite this prevalence of inappropriate medication usage, Coe et al. found that older adults with AD/ADRD were less likely to be eligible for Medicare medication therapy management or receive a comprehensive medication review than those without dementia.[46]

Therapeutics

The development of anti-dementia therapeutics should center patient priorities and access. When asked, patients and caregivers identified that the most important anti-AD treatment characteristics were its ability to improve symptoms and its safety profile.[37,47] Caregivers were generally more concerned about potential adverse events than patients, who focused on the potential benefit.[37] However, the high cost of anti-AD treatments (e.g., lecanemab) was consistently identified as an access issue.[37,47,48] Relatedly, anti-AD treatment was generally utilized more by patients with higher SES.[48,49] Access to lecanemab, which requires access to a positron emission tomography scan and an infusion center, is affected by socioeconomic and geographic factors.[47] Patients in rural areas were less likely to receive anti-AD medication.[49,50] Perez-Arce et al. conducted a discrete choice experiment to investigate Americans' willingness to pay for an AD treatment that reduces disease progression by 30%, finding that respondents would be willing to pay $252 per year or .59% of their earned income on average.[51] This would make the average valuation of AD treatment between $33.7 and $51.4 billion annually.[51] The high cost and perceived modest benefits of lecanemab make its valuation highly influenced by patients' and caregivers' financial circumstances. However, improving access to effective treatments would be beneficial both to patients and society by potentially reducing healthcare spending. This idea was supported by an article using a machine learning model to study the economic effects of using anti-dementia drugs. The investigators found that patients who took these treatments, specifically cholinesterase inhibitors, had significantly reduced Medicare and inpatient costs.[52]

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