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ADRD and Long-Term Care: Research Opportunities and Challenges

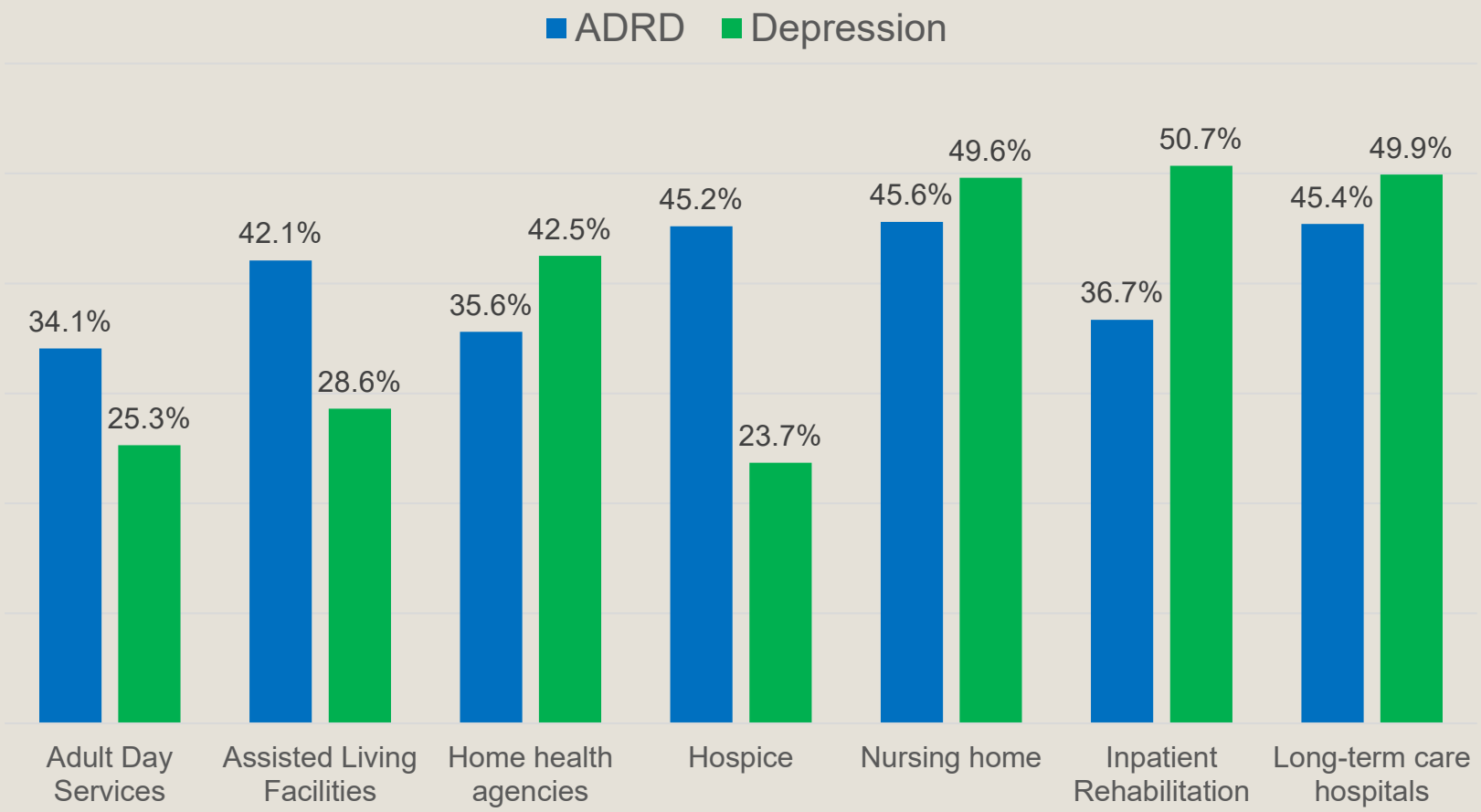
David C. Grabowski, PhD

March 6, 2025

Talk Overview

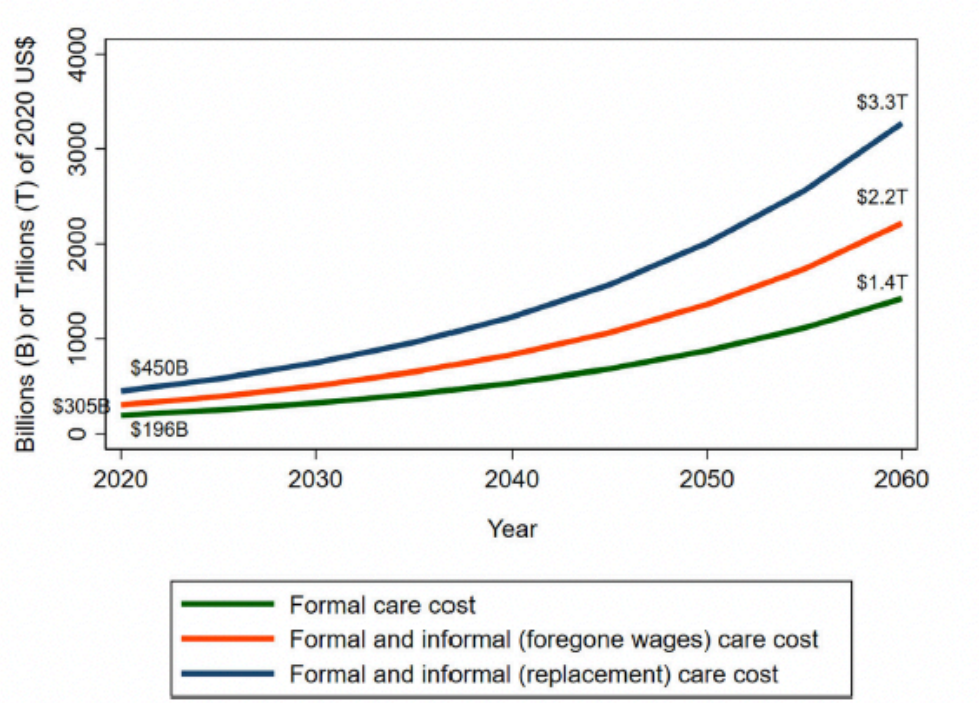
- Alzheimer's Disease and related dementias (ADRD) in LTC
- Barriers to high value care
- Policy opportunities for improving care
- Research needs
- Concluding thoughts

ADRD is frequent



NCHS, 2020 National Post-acute and Long-term Care Study

ADRD care is expensive



Nandi et al. 2024 npj Aging

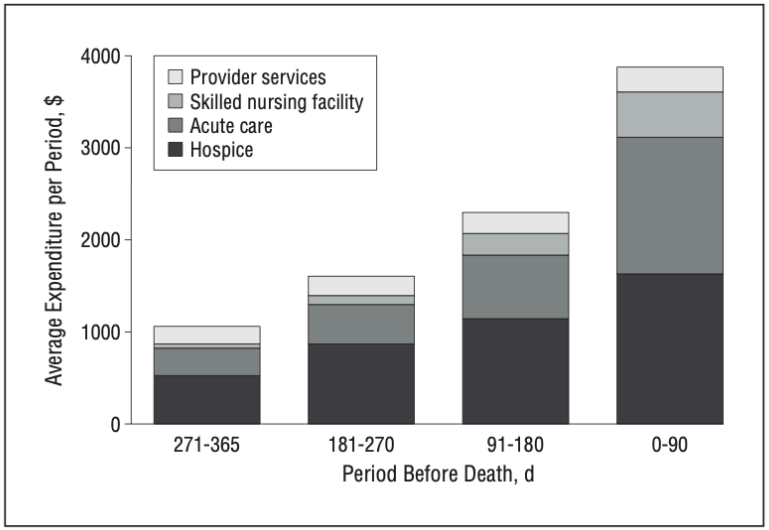


Figure 2. Mean Medicare expenditures for nursing home residents with advanced dementia in the last year of life during the following 90-day intervals: 0 to 90 days before death (n=177); 91 to 120 days before death (n=128); 121 to 270 days before death (n=96); and 365 to 271 days before death (n=68).

Goldfeld et al. 2011 JAMA IM

ADRD patients rely heavily on family caregivers

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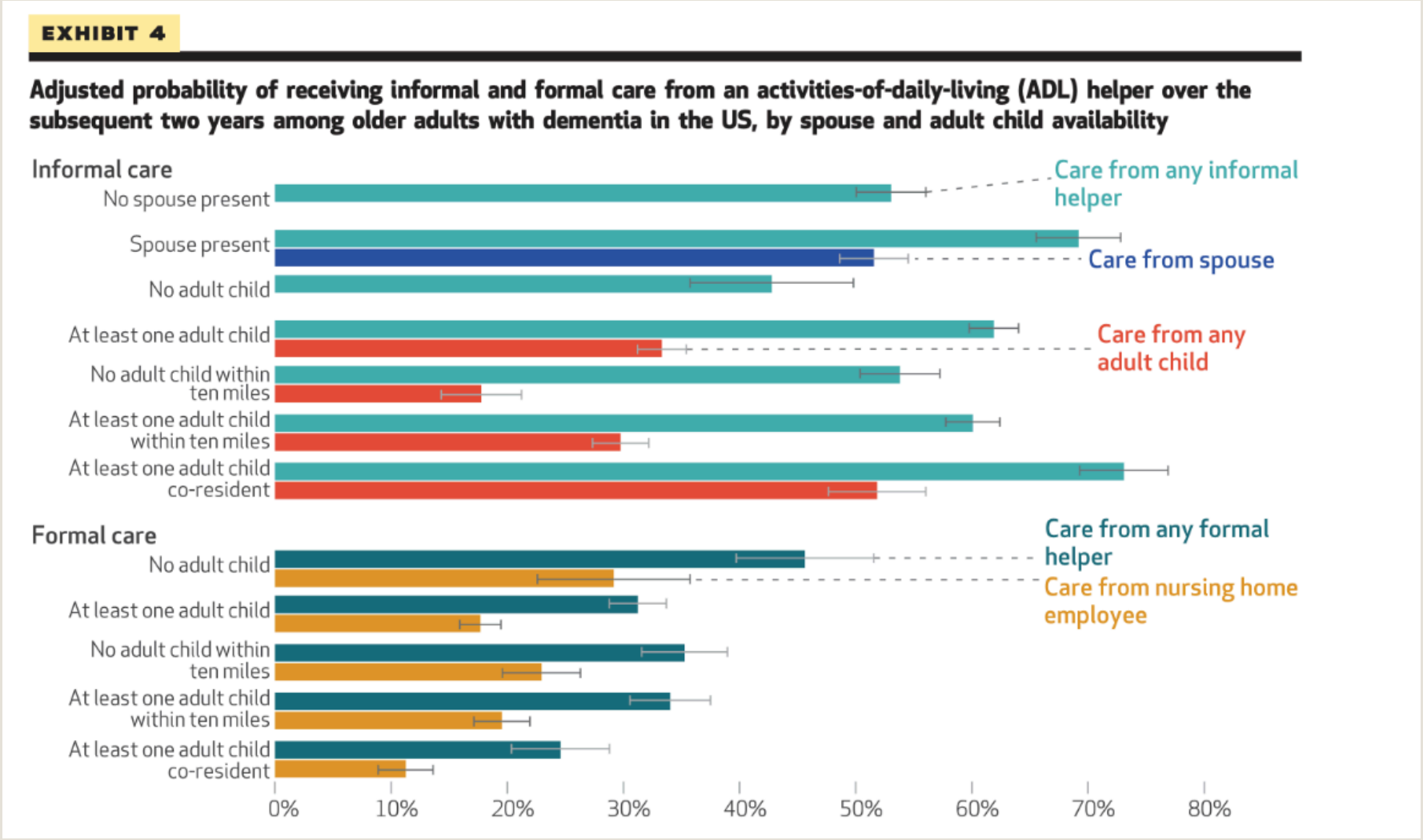
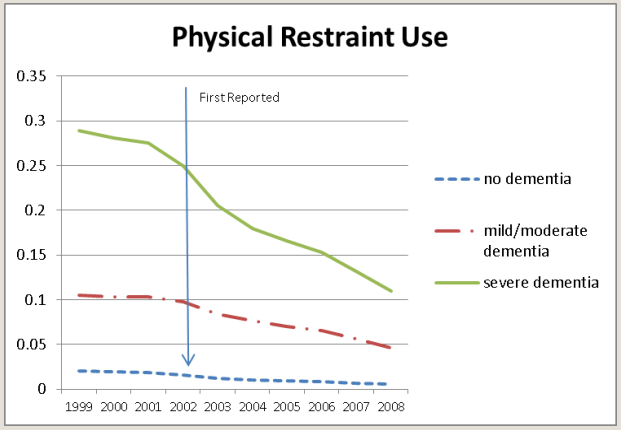
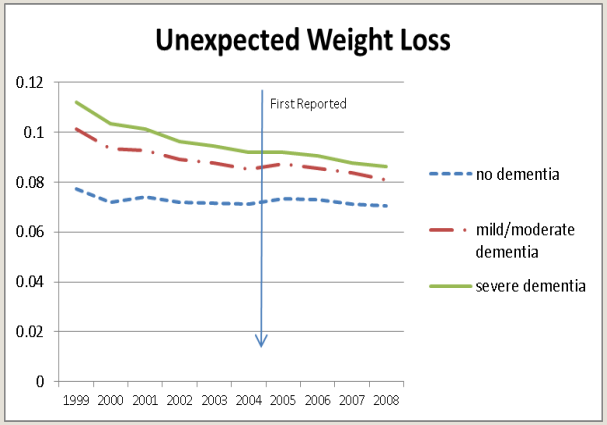


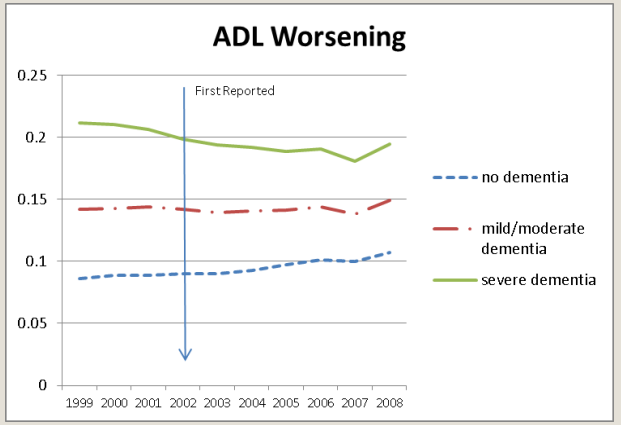
Choi et al. 2021 Health Affairs

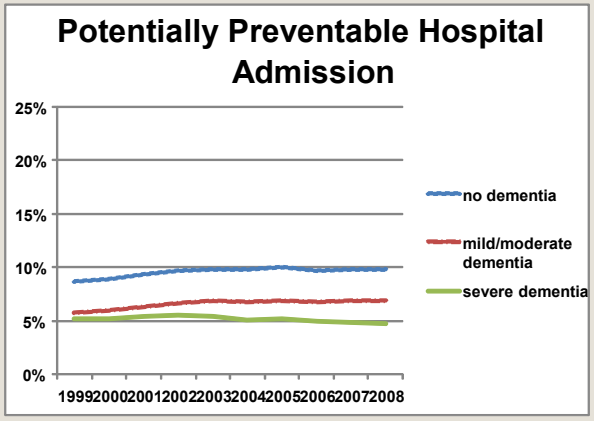
ADRD Care Often of Poor Quality

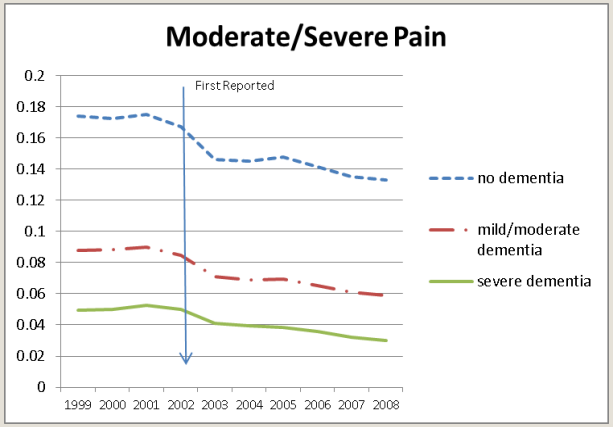
Nursing home quality by dementia status among chronic-care residents, 1999-2008

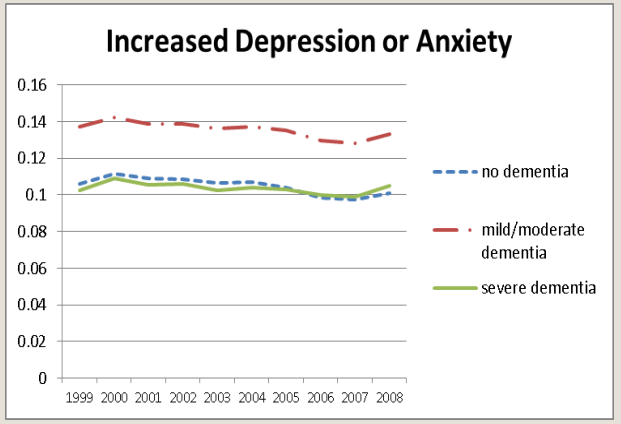












Konetzka et al., 2016, MCRR

ADRD can be studied in LTC using range of datasets

- Medicare FFS claims
- MA encounter data
- Medicaid claims
- Assessment data: minimum data set (MDS) and Outcome and Assessment Information Set (OASIS)
- Survey data: HRS, NHATS, etc.
- Electronic health records

Policy challenges of caring for long-term care recipients with ADRD

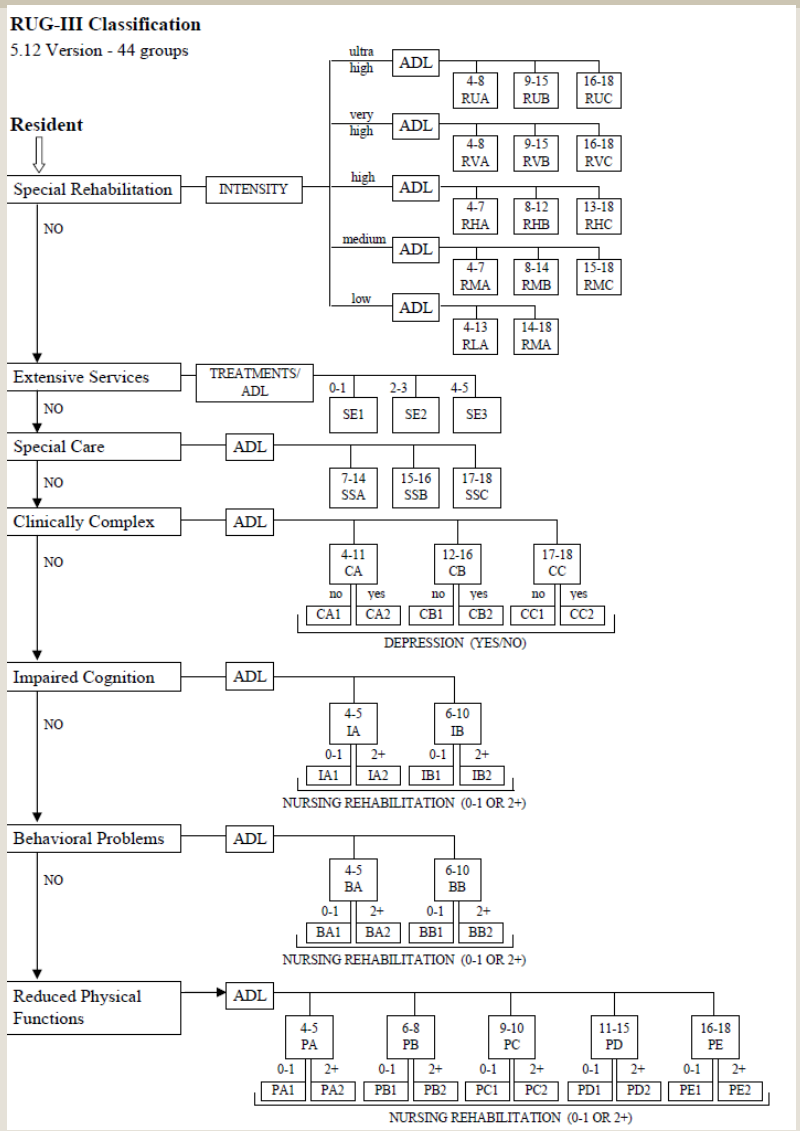
Individuals with ADRD encounter all the same policy challenges as other long-term care recipients, only more so.

Barriers to high value care

- Inadequate payment
- Incomplete information on quality
- Fragmentation of long-term care and health care services

How does Medicaid reimburse nursing homes for residents with dementia?

Historically, Medicare & most Medicaid systems case-mix adjusted payments based on resource utilization groups (or RUGs)



Issues with RUGs Medicaid nursing home payment

- Low payment rate for ADRD residents
- Payment formulae did not adequately account for interaction of ADRD and physical limitations
- Poor incentive to provide high-quality Alzheimer's care

Problem #1: Low payment for Dementia patients

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Texas Medicaid per diems by RUGs (FY '15)

Rehabilitation:	$141-$193/day
Extensive services:	$170-$230/day
Special care:	$156-$166/day
Clinically complex:	$106-$136/day
Impaired cognition:	$91-$113/day
Behavioral problems:	$85-$111/day
Reduced physical function:	$82-$120/day

http://www.hhsc.state.tx.us/rad/long-term-svcs/downloads/2015-nf-rates.pdf

Problem #2: Payment ignores dementia in other categories

- Rehabilitation
- Extensive services
- Special care
- Clinically complex

No adjustment for cognitive impairment

- Impaired cognition (CPS≥3; ADL score<11)

- Behavioral problems
- Reduced physical functioning

No adjustment for mild impairment

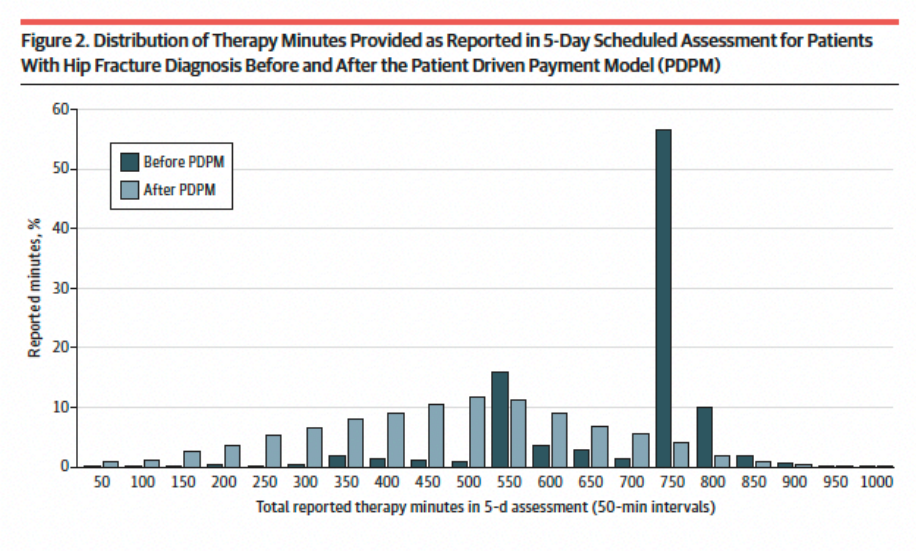
Problem #3: No reward for providing high quality dementia care

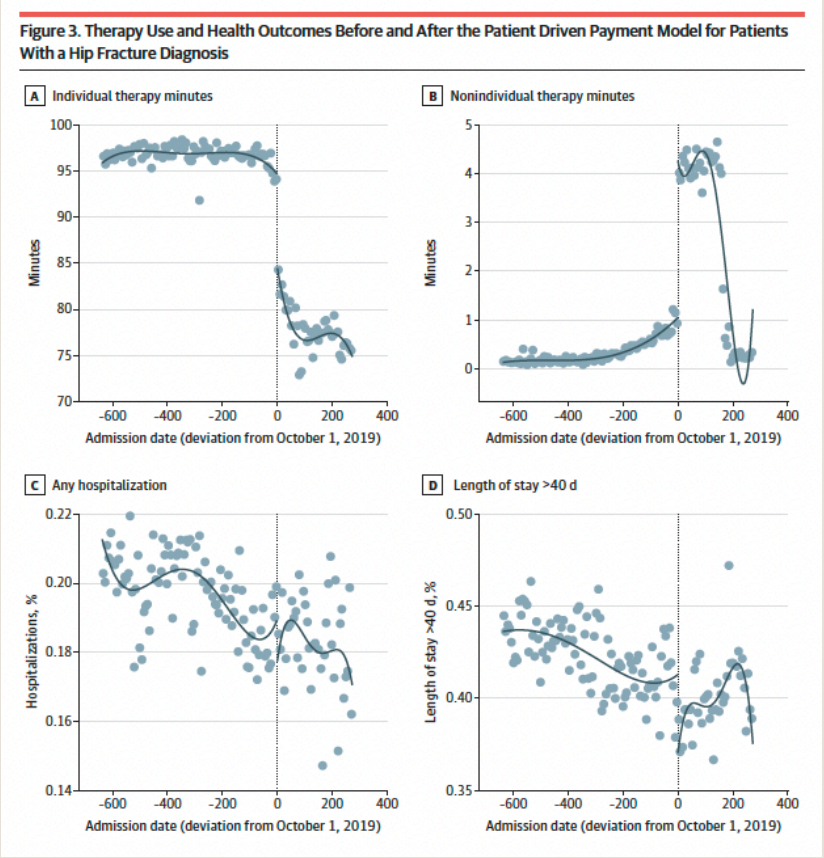
Under RUGS payment system, little incentive to:

- Develop and invest in best practices
- Provide person-centered care
- Ensure good outcomes

Patient-Driven Payment Model (PDPM)

Medicare (Oct 2019) & Medicaid nursing home payment systems shifted from RUGs to PDPM, which is based on patient characteristics





Rahman et al., 2022, JAMA HF

No change in ADRD admits but increased ADRD coding

Exhibit 2 Change in Elixhauser comorbidity index computed from diagnoses submitted by hospitals skilled nursing facilities, before and after implementation of the Patient Driven Payment Model (PDPM).

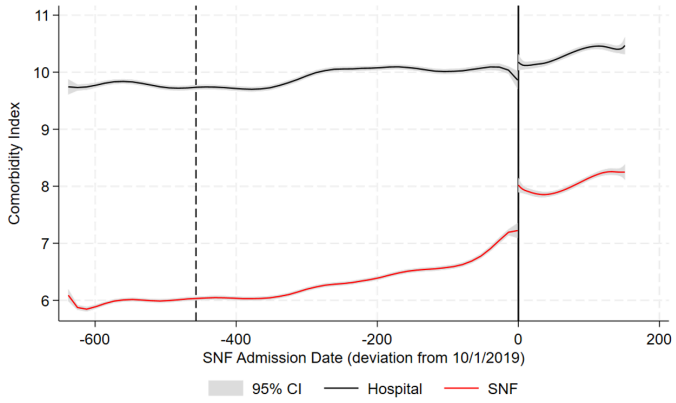
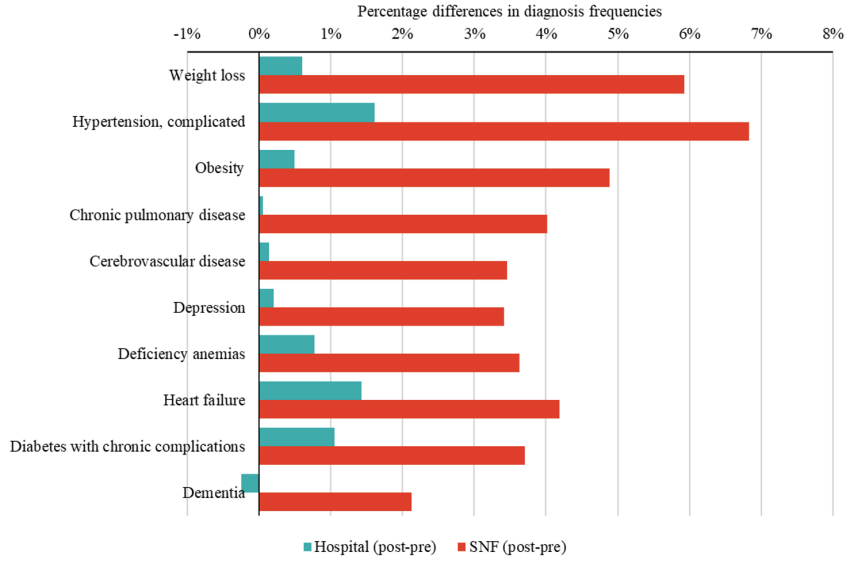


Exhibit 3 Changes in frequencies of specific diagnoses in hospitals and skilled nursing facilities before and after implementation of the Patient Driven Payment Model (PDPM).



Geng et al., 2025, Working paper

No change in quality for ADRD patients despite higher spending, longer LOS, less therapy

Exhibit 4 Adjusted discontinuity of clinical outcomes and expenditures across patient cohorts before and after implementation of the Patient Driven Payment Model.

	30-day rehospitalization rate	30-day mortality rate	SNF expenditure ($)	SNF length of stay (day)	SNF therapy min/d
ADRD	-0.034%	0.016%	723.6***	0.780**	-9.183***
(n=887,169)	(-1.16, 1.10)	(-0.778, 0.810)	(368.6, 1,078)	(0.025, 1.535)	(-10.14 - -8.226)

Notes: ADRD = Alzheimer's Disease and Related Dementia, SNF = skilled nursing facilities. Each cell includes a point estimate and 95% confidence interval in the parentheses. Three stars (***) indicate p<0.01, two stars (**) indicate p<0.05 and one star (*) indicate p<0.1. Regression discontinuity models were adjusted for demographic and clinical characteristics.

Geng et al., 2025, Working paper

Incomplete Information

- Nursing home residents with Alzheimer's Disease may lack resources to ascertain and monitor quality of care
  - Cognitive impairment
  - Lack of availability of family
  - Urgency of care decision

- Grabowski and Mitchell (2009 Med Care) found a U-shaped relationship between family oversight and quality problems for nursing home residents with advanced dementia

Patients with ADRD discharged to worse SNFs

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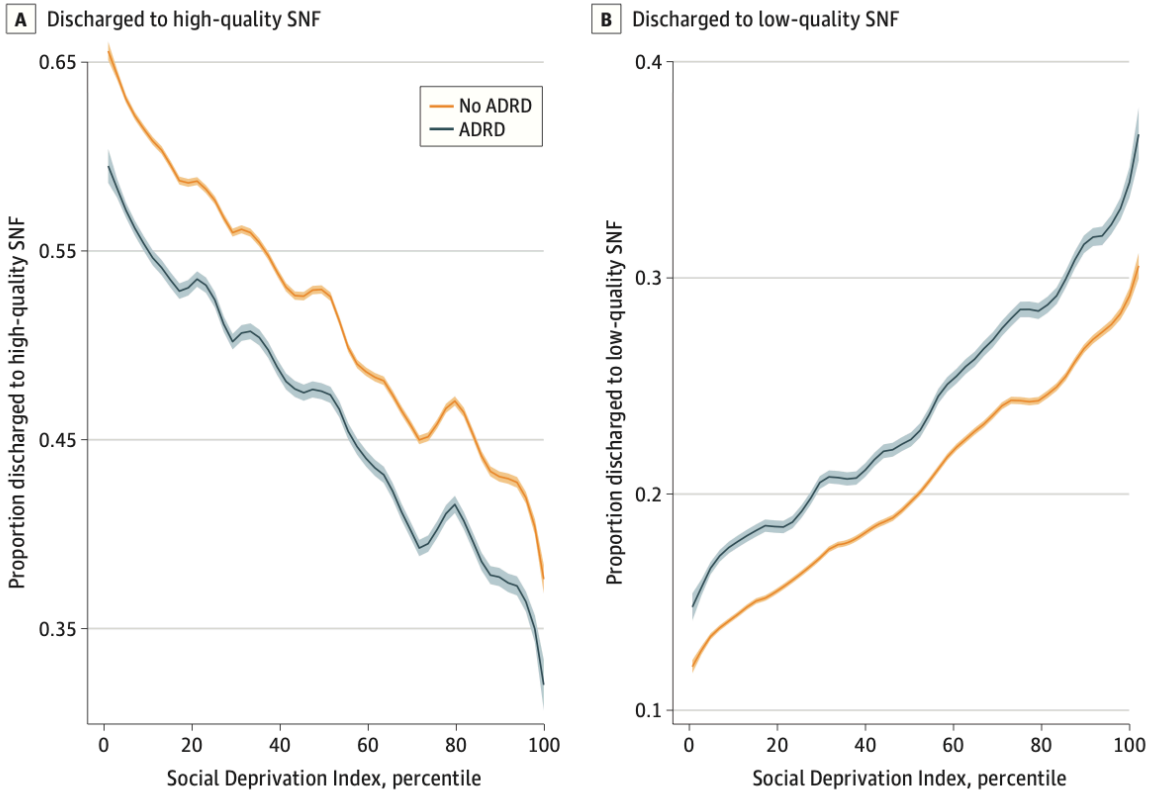
Figure 1. Differences in Skilled Nursing Facility (SNF) Quality Across Neighborhoods by Alzheimer Disease and Related Dementias (ADRD) Status



High-quality SNFs are those with 4- or 5-star staffing ratings (scored 1 to 5). Low-quality SNFs are those with 1- or 2-star staffing ratings. Smooth curves and 95% CIs were estimated using local polynomial regression. Solid lines indicate the estimated probability of entry to low- and high-quality SNFs at each Social Deprivation Index level; shaded areas, 95% CIs.

Kosar et al., 2023, JAMA NO

Fragmentation of nursing home care and health care services

Dementia patients require a mix of health and LTC services, with each service delivered in its own silo

Use	Incident Dementia (n=999)	No Dementia (n=2,674)
Any hospital stay	86.0%	51.2%
Total avg. hospital days	30.7	9.7
Any nursing home use	49.3%	13.9%
Total avg. NH days	158.1	15.5
Any home health care	65.2%	27.3%
Died	38.4%	21.2%

Callahan et al., JAGS 2012

Fragmentation results from payment and delivery failures…

- ***Payment failure:*** Medicaid pays for nursing home care but does not share in any Medicare savings associated with reductions in health care use for residents with dementia

- ***Delivery failure:*** Nursing homes do not invest in infrastructure and expertize to treat residents with dementia safely in the nursing home setting

Opportunities for Policy Reform

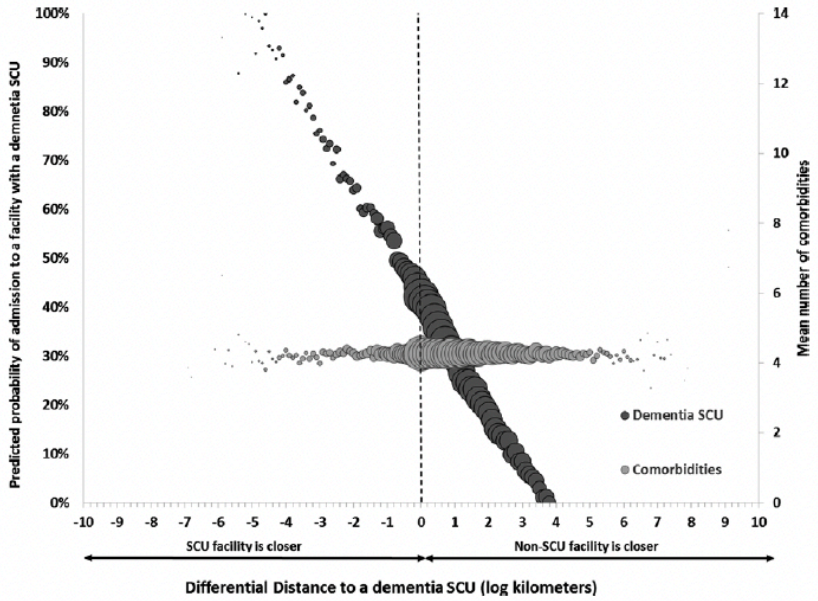
Reimbursement	Information	Coordination
Increase payment/change case-mix	Report cards	Global payment-delivery models
Pay-for-performance	Regulation	

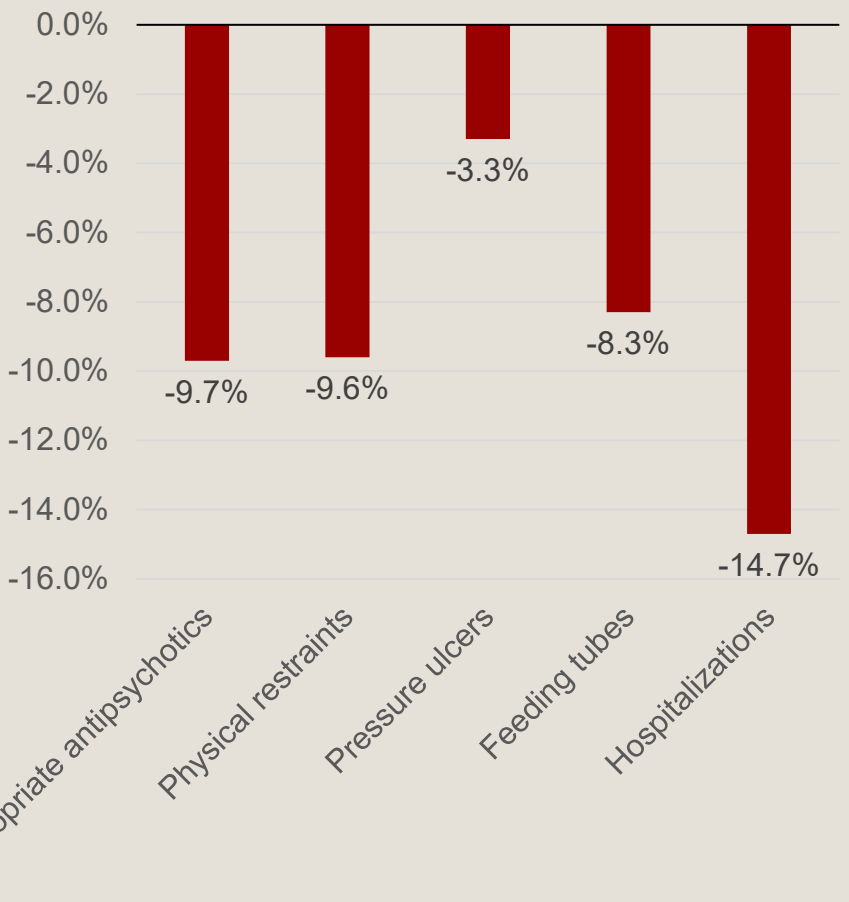
Nursing Home Payment

- Generosity and method of nursing home payment have strong impact on access and quality of care
- Some states (IA, NY) have had Medicaid nursing home rate add-ons for dementia residents
- Some states also pay higher rates for care in dementia SCUs

Effect of dementia SCUs on nursing home quality

Figure 1: Scatter Plot of the Adjusted Predicted Probability of Admission to a Facility with a Dementia Special Care Unit (SCU) and Mean Number of Comorbidities by the Differential Distance to a Facility with versus without a Dementia SCU





Joyce et al., 2018, HSR

Nursing Home Report Cards

Report cards can provide valuable information for dementia patients & their families on quality of care

Following introduction of Nursing Home Compare:

- No change in ADRD quality (reported or unreported dimensions)
- No change in ADRD admissions
- Some increased coding of ADRD

Konetzka et al., 2016, MCRR

Example of unintended consequence

- Physical restraints and overuse of antipsychotics are examples of poor care practices for NH residents with dementia
- Physical restraints were reported on federal report card (NH Compare), while antipsychotics were not
- NH Compare led to decrease in physical restraints among dementia patients, while antipsychotic use increased
- Roughly 36% of the increase in antipsychotic use may be attributable to public reporting of physical restraints

Konetzka et al., 2014, JAGS

Example of unintended consequence, part 2

- Inappropriate antipsychotics were added to NH Compare starting in 2015
- Schizophrenia, Tourette's syndrome, Huntington's disease are considered "appropriate" under antipsychotic measure (or qualifying conditions)
- We compared facility reported MDS-based measure against Medicare claims:
  - Underreporting (87% reporting rate) in facility-reported antipsychotic use versus Medicare claims
  - Only 54.8% of schizophrenia, 46.5% of Tourette's syndrome, and 72.4% of Huntington's disease diagnoses reported in the MDS had a claims diagnosis

Chen & Grabowski, 2023, HA Scholar

Care Coordination

- Need to identify models that coordinate LTC and health care payment and delivery for individuals with Alzheimer's Disease

- Lots of potential models:
  - Accountable care organizations (ACOs)
  - Integrated care demonstrations
  - MA Special Needs Plans

Health Quality and Utilization Outcomes of NH Residents With Advanced Dementia, by Health Insurance Status

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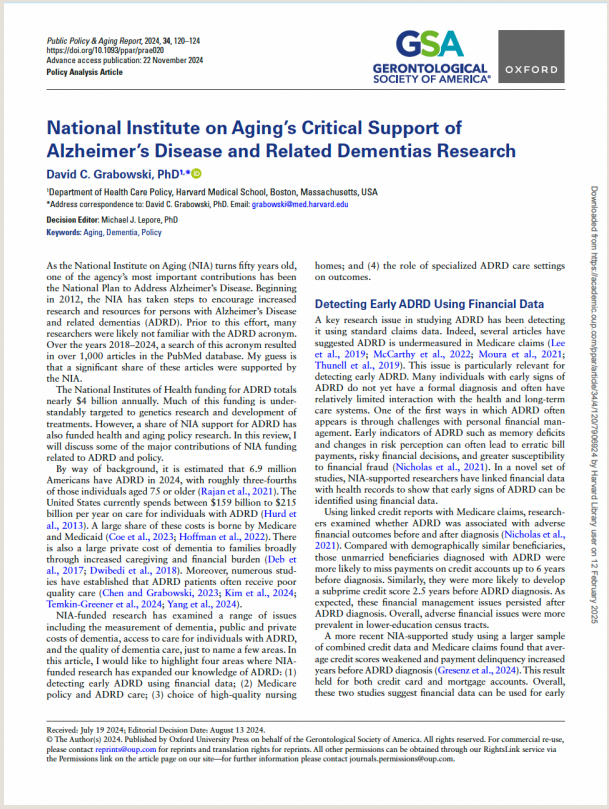
Outcome	Fee for Service		Managed Care		Managed-Care Estimate (95% CI)[a]	
	No.	Mean (SD) or %	No.	Mean (SD) or %	Unadjusted	Adjusted[b]
Do-not-hospitalize orders[c]	852	50.9	703	63.7	1.9 (1.0 to 3.7)[d]	1.9 (1.1 to 3.4)[d]
Hospital transfers for acute illness[e,f]	331	15.7	229	3.8	0.3 (0.1 to 0.7)[d]	0.2 (0.1 to 0.5)[d]
Primary care visits in the nursing home in 90 d[g]	158	4.2 (5.0)	133	4.8 (2.6)	1.3 (1.1 to 1.6)[d]	1.3 (1.1 to 1.6)[d]
Physician visits	158	3.4 (4.7)	133	1.8 (1.5)	0.76 (0.6 to 0.9)[d]	0.7 (0.6 to 0.9)[d]
Nurse practitioner visits	158	0.8 (2.6)	133	3.0 (2.1)	3.0 (2.1 to 4.2)[d]	3.0 (2.2 to 4.1)[d]
Hospice treatment[g]	158	18.4	133	23.3	0.9 (0.5 to 1.5)	0.8 (0.4 to 1.5)
Family satisfaction with care (SWC-EOLD)[c,h]	638	31.6 (4.6)	538	32.3 (4.5)	1.0 (0.0 to 2.1)	0.9 (0.0 to 1.8)
Comfort in preceding 90 d (SM-EOLD)[c,i]	762	37.5 (7.6)	634	37.8 (7.5)	0.9 (−2.9 to 2.7)	0.1 (−1.7 to 1.8)
Comfort during last week of life (CAD-EOLD)[e,j]	81	34.9 (4.6)	66	34.0 (4.2)	−0.8 (−2.3 to 0.7)	−0.7 (−2.2 to 0.8)
Pain treatment[e]	147	10.2	114	16.7	1.8 (0.0 to 3.5)	1.6 (0.7 to 3.5)
Dyspnea treatment[e]	124	61.3	94	55.3	0.9 (0.5 to 1.8)	0.9 (0.4 to 2.0)
Pneumonia treatment[e]	127	100.0	79	100.0	...	...
Antimicrobial agent						
None	10	7.9	8	10.1	...	...
Oral	71	55.9	44	55.7	0.8 (0.3 to 2.1)	1.5 (0.4 to 4.9)
Intramuscular	16	12.6	17	21.5	1.3 (0.2 to 2.4)	2.9 (0.7 to 11.7)
Intravenous or hospitalization	30	23.6	10	12.7	0.4 (0.1 to 1.3)	0.6 (0.1 to 2.2)

Goldfeld et al., JAMA Intern Med 2013

Lots of NIA contributions to ADRD research



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Policy Analysis Article

GSA GERONTOLOGICAL SOCIETY OF AMERICA · OXFORD

National Institute on Aging's Critical Support of Alzheimer's Disease and Related Dementias Research

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Decision Editor: Michael J. Lepore, PhD
Keywords: Aging, Dementia, Policy

As the National Institute on Aging (NIA) turns fifty years old, one of the agency's most important contributions has been the National Plan to Address Alzheimer's Disease. Beginning in 2012, the NIA has taken steps to encourage increased research and resources for persons with Alzheimer's Disease and related dementias (ADRD). Prior to this effort, many researchers were likely not familiar with the ADRD acronym. Over the years 2018–2024, a search of this acronym resulted in over 1,000 articles in the PubMed database. My guess is that a significant share of these articles were supported by the NIA.

The National Institutes of Health funding for ADRD totals nearly $4 billion annually. Much of this funding is understandably targeted to genetics research and development of treatments. However, a share of NIA support for ADRD has also funded health and aging policy research. In this review, I will discuss some of the major contributions of NIA funding related to ADRD and policy.

By way of background, it is estimated that 6.9 million Americans have ADRD in 2024, with roughly three-fourths of those individuals aged 75 or older (Rajan et al., 2021). The United States currently spends between $159 billion to $215 billion per year on care for individuals with ADRD (Hurd et al., 2013). A large share of these costs is borne by Medicare and Medicaid (Coe et al., 2023; Hoffman et al., 2022). There is also a large private cost of dementia to families broadly through increased caregiving and financial burden (Deb et al., 2017; Dwibedi et al., 2018). Moreover, numerous studies have established that ADRD patients often receive poor quality care (Chen and Grabowski, 2023; Kim et al., 2024; Temkin-Greener et al., 2024; Yang et al., 2024).

NIA-funded research has examined a range of issues including the measurement of dementia, public and private costs of dementia, access to care for individuals with ADRD, and the quality of dementia care, just to name a few areas. In this article, I would like to highlight four areas where NIA-funded research has expanded our knowledge of ADRD: (1) detecting early ADRD using financial data; (2) Medicare policy and ADRD care; (3) choice of high-quality nursing homes; and (4) the role of specialized ADRD care settings on outcomes.

Detecting Early ADRD Using Financial Data

A key research issue in studying ADRD has been detecting it using standard claims data. Indeed, several articles have suggested ADRD is undermeasured in Medicare claims (Lee et al., 2019; McCarthy et al., 2022; Moura et al., 2021; Thunell et al., 2019). This issue is particularly relevant for detecting early ADRD. Many individuals with early signs of ADRD do not yet have a formal diagnosis and often have relatively limited interaction with the health and long-term care systems. One of the first ways in which ADRD often appears is through challenges with personal financial management. Early indicators of ADRD such as memory deficits and changes in risk perception can often lead to erratic bill payments, risky financial decisions, and greater susceptibility to financial fraud (Nicholas et al., 2021). In a novel set of studies, NIA-supported researchers have linked financial data with health records to show that early signs of ADRD can be identified using financial data.

Using linked credit reports with Medicare claims, researchers examined whether ADRD was associated with adverse financial outcomes before and after diagnosis (Nicholas et al., 2021). Compared with demographically similar beneficiaries, those unmarried beneficiaries diagnosed with ADRD were more likely to miss payments on credit accounts up to 6 years before diagnosis. Similarly, they were more likely to develop a subprime credit score 2.5 years before ADRD diagnosis. As expected, these financial management issues persisted after ADRD diagnosis. Overall, adverse financial issues were more prevalent in lower-education census tracts.

A more recent NIA-supported study using a larger sample of combined credit data and Medicare claims found that average credit scores weakened and payment delinquency increased years before ADRD diagnosis (Gresenz et al., 2024). This result held for both credit card and mortgage accounts. Overall, these two studies suggest financial data can be used for early

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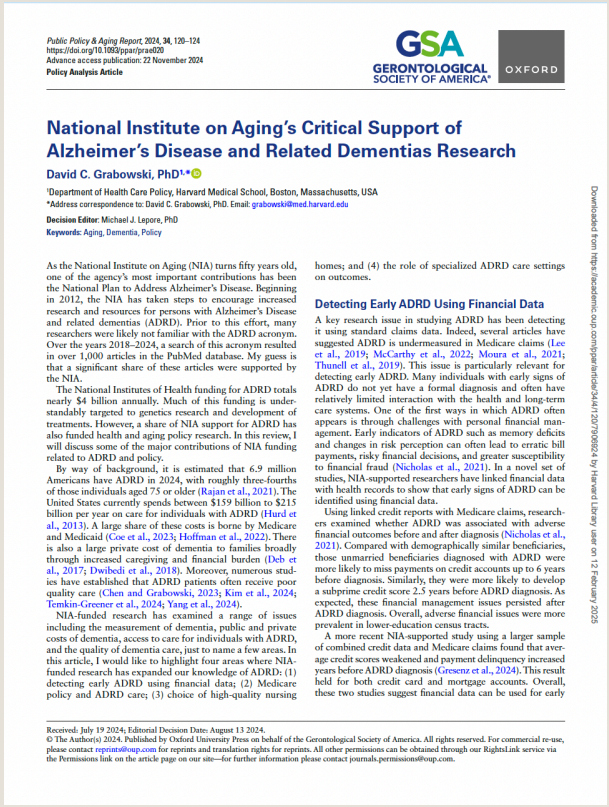
- Detecting early ADRD using financial data
- Medicare and ADRD care
- Role of specialized long-term care for ADRD
- Access to high quality long-term care

Lots of work left to be done



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GSA GERONTOLOGICAL SOCIETY OF AMERICA | OXFORD

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A key research issue in studying ADRD has been detecting it using standard claims data. Indeed, several articles have suggested ADRD is undermeasured in Medicare claims (Lee et al., 2019; McCarthy et al., 2022; Moura et al., 2021; Thunell et al., 2019). This issue is particularly relevant for detecting early ADRD. Many individuals with early signs of ADRD do not yet have a formal diagnosis and often have relatively limited interaction with the health and long-term care systems. One of the first ways in which ADRD often appears is through challenges with personal financial management. Early indicators of ADRD such as memory deficits and changes in risk perception can often lead to erratic bill payments, risky financial decisions, and greater susceptibility to financial fraud (Nicholas et al., 2021). In a novel set of studies, NIA-supported researchers have linked financial data with health records to show that early signs of ADRD can be identified using financial data.

Using linked credit reports with Medicare claims, researchers examined whether ADRD was associated with adverse financial outcomes before and after diagnosis (Nicholas et al., 2021). Compared with demographically similar beneficiaries, those unmarried beneficiaries diagnosed with ADRD were more likely to miss payments on credit accounts up to 6 years before diagnosis. Similarly, they were more likely to develop a subprime credit score 2.5 years before ADRD diagnosis. As expected, these financial management issues persisted after ADRD diagnosis. Overall, adverse financial issues were more prevalent in lower-education census tracts.

A more recent NIA-supported study using a larger sample of combined credit data and Medicare claims found that average credit scores weakened and payment delinquency increased years before ADRD diagnosis (Gresenz et al., 2024). This result held for both credit card and mortgage accounts. Overall, these two studies suggest financial data can be used for early

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- Examine ADRD specific outcomes (e.g., burden on family caregivers)
- Examine non-traditional outcomes (e.g., isolation, financial security, housing)
- Examine root causes of ADRD patients' health and LTC use
- What delivery-level innovations work? Why has adoption been so limited?

Concluding Thoughts

- Persons with ADRD face challenges in accessing high quality long-term care, including inadequate payment, limited quality information, and care fragmentation
- Opportunities for reform include payment changes, report cards, and greater care coordination
- More research needed on all these options

Thank You

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