

NATIONAL RESEARCH SUMMIT ON CARE, SERVICES, AND SUPPORTS FOR PERSONS WITH DEMENTIA AND THEIR CAREGIVERS

Providing High-Quality Care In Medical Care Settings

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Disclosures

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30,000 Foot Overview

- Focus on models of care intended to improve care quality and outcomes for persons living with dementia and their care partners
- Models reflect attention:
 - to whom (dyad versus individuals)
 - delivered where (medical offices, homes, community-based settings)
 - delivered how (face to face, telephone, video, internet)
- Model designs raise structural and systems issues – standalone, primary care embedded, specialty clinic or program, hospital, skilled nursing facility, degrees of interaction with other components of health care system (especially, primary care)

Themes addressed: 1) Perspectives of persons living with dementia and/or caregivers; 2) Health disparities; 3) Technology

Dementia Care Models: Efficacy and Commonality

- Well over 200 caregiver interventions are efficacious*
- Most demonstrated benefits have been small but clinically and statistically significant nonetheless
- Much of the focus of these interventions (whether caregiver-only or having specific medical care integration) have strong commonalities
- Reflects issues and needs that are universal to this population:
 - Loss of personal agency and the need for someone else to provide support and direct care (“not necessarily what I signed up for”)
 - Increased use of healthcare and supportive services and increased cost

* Gitlin, et al. *The Gerontologist*, 2015, Vol. 55, No. 2, 210–226

Feasibility and Sustainability

- Interrelated concepts
- Some tested models have remained in existence, others not
- Even for those in use, spread or access is relatively small
(14% evidence implemented into practice)¹
- Model sustainability or spread may not reflect relative value

Organization Structure	Organizational Culture
Financing (Reimbursement /Philanthropy)	Competing Priorities
Healthcare System*	Clinical Champions (come and go)
Surrounding (internal/external) resources	Expansive versus Conservative
*Accountable Care Organization, Academic, Non-Academic	

¹Institute of Medicine, 2008

Comprehensive Models – Dyadic-Focused

- Community-based
 - BRI Care Consultation¹
 - MIND at Home (Hopkins)²
 - The Care Ecosystem (UCSF)³
- Health System-based
 - Indiana University Healthy Aging Brain Center (HABC)⁴
 - The UCLA Alzheimer's and Dementia Care Program (UCLA ADC)⁵
 - Integrated Memory Care Clinic (Emory)⁶



¹ Bass DM, et al *Innov Aging*. 2019.

² Samus QM et al. *Contemp Clin Trials*. 2018;71:103–112. doi:10.1016/j.cct.2018.05.009

³ Possin KL, et al *JAMA Intern Med*. 2019 Sep 30.

⁴ Callahan CM et al. *Health Aff (Millwood)*. 2014;33(4):626–632.

⁵ Reuben DB, et al *J Am Geriatr Soc*. 2019 Nov;67(11):2267–2273.

⁶ Clevenger CK, et al. *J Am Geriatr Soc*. 2018 Dec;66(12):2401–2407.

Courtesy of David Reuben, MD

Dementia Care Models: Common Features

- Direct care of dyad (psychosocial, +/- medical care)
- Problem focused
- Mix of non-professional (trained) and professional providers – often working together (professions: advanced practice nurse, nurse, social worker, pharmacist, psychologist, (physician))
- Provide: psychosocial support, counseling, knowledge (including behavioral strategies), medical interventions (medications), planning
- Few are pragmatic or “embedded”

Transition Care Models for PLWD

- Some models particularly focused on care transitions although the issues specific to transitions should be within the purview of a comprehensive care model:
 - Medication reconciliation
 - Care recommendations (disease management)
 - Behavior change
 - Caregiver stress / burden
 - Anticipatory guidance

Kind AJ, et al. Health Aff (Millwood). 2012;31(12):2659–2668.
Naylor MD, et al. J Comp Eff Res. 2014;3(3):245–257.



Have We Seen Enough Research on Dementia Care Models?

- One universal model type unlikely to succeed everywhere (“all politics are local”) – some scalable , some not
- Multiple examples listed before (using care navigators-dementia specialist teams by telephone; versus care managers who meet in person)
- *Best Practice Caregiving – Dementia Care Programs*
 - Benjamin Rose Institute on Aging and Family Caregiver Alliance
 - National Database of over 40 programs

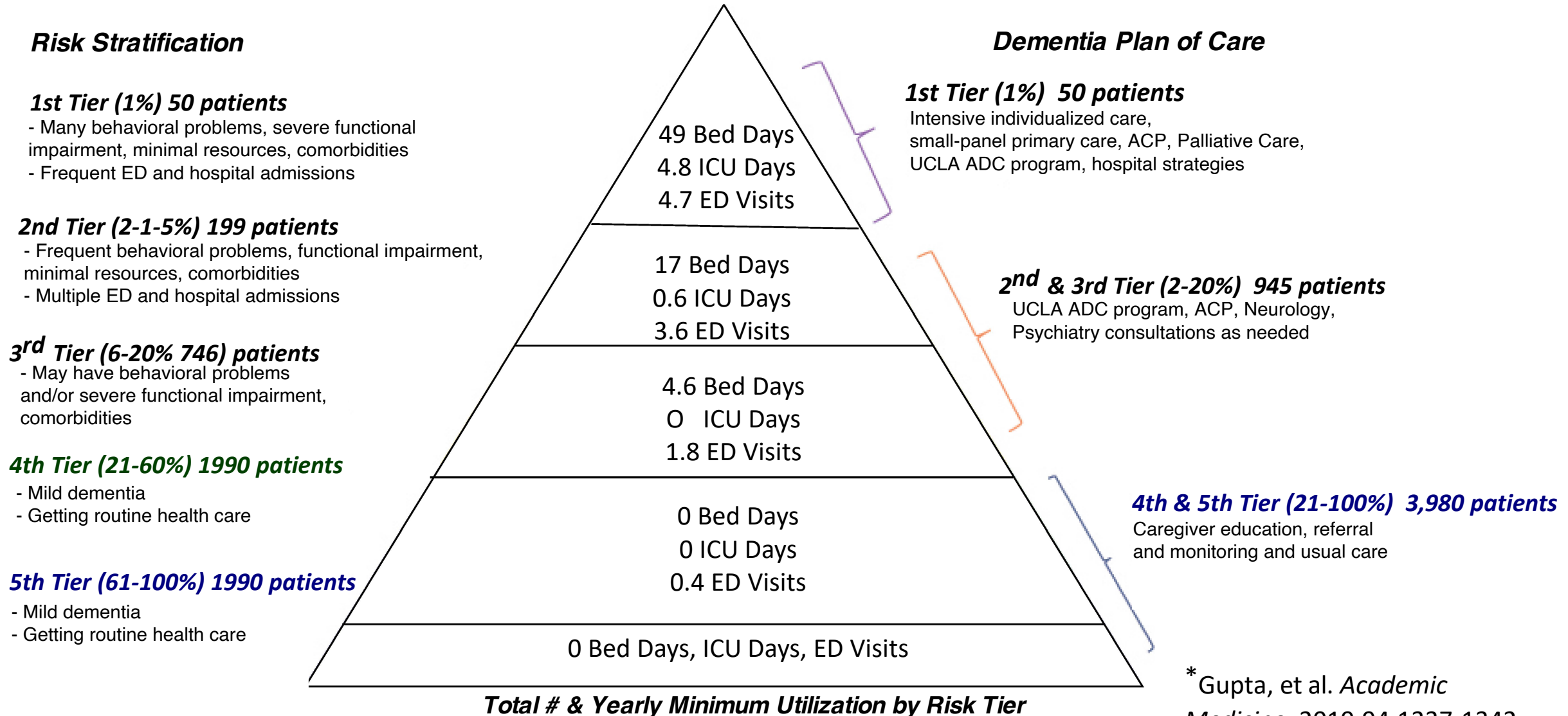
Focus of each Program	Program Implementation
Research findings	Direct Utilization Experiences of Delivery Sites
Program Developer Information	Updated Annually

Patient-Only Care

- Dementia-care models are largely caregiver focused – majority are not integrated directly into a medical care system
- Published models do not address what to do about the individual cognitively impaired patient (without care partner), often undiagnosed, even if recognized
- An absence of primary care capacity for dementia capability has enabled “persistent neglect”
- Increasing provider interest in dementia practice change (but largely education only, e.g., KAER – Maslow and Fortinsky)*
- If we are to “outsource” dementia care, in what ways does primary care need to change to achieve effectiveness?

*Source: <https://www.geron.org/programs-services/alliances-and-multi-stakeholder-collaborations/cognitive-impairment-detection-and-earlier-diagnosis>

Population-based Dementia Care Model*



Should severity play a prescriptive role?

* Gupta, et al. *Academic Medicine*. 2019;94:1337-1342.

Courtesy of David Reuben, MD

Do we know what are the most meaningful care interventions especially for those who are from underrepresented groups?

- How do we best achieve concordance between our “results” and what is most important to patients and care partners (goals)?
- Do we know whether we should be asking different questions in different ways of people from underrepresented groups?
- Can we build some attention to issues of trust for people from underrepresented groups?
- How do we identify and address competing priorities for patients and families?
- Is there a best strategy for “triadic” encounters (patient, care partner, and provider together in same moment of care)?

Can Primary Care Embedded Programs “Work”?

- We know models that “recommend” care interventions to primary care providers don’t work!
- What is the capacity of the primary care physician/network for delivering effective dementia care?
- What are the challenges: risks/benefits of embedded versus free-standing but integrated models?
- Should we first know the “minimum effective dose” before “outsourcing” scalable dementia care

Borson S. J Gen Intern Med. 2007 Jun;22(6):811-7.

Boustani M, et al. Int J Geriatr Psychiatry. 2006 Jun;21(6):556-63.

Is there a Minimum Effective Dose?

- Care deliverer: physician, advanced practice nurse, nurse, social worker, other office staff, psychologist, community health navigator, peers, community centers, (combinations of these)
- Intensity of care: length of encounter(s), depth of encounter(s)
- Frequency of care: scheduled (how often), episodic, or both
- Method of prioritization of issues: (provider drive, dyad driven)

Many other questions....

- Can we re-engineer primary care practice for dementia care? (different than incorporating dementia care into primary care practice)?
- Can we better phenotype dyads (beyond measures of dementia severity and traditional demographics) looking to predict level/type of need to test a variety of strategies for comparative effectiveness?
- Does the delivery medium (in-person, telephone, video, email, web) matter and can we predict for whom?
- Are there point of care delivery opportunities that have greatest effectiveness (e.g., office, home, ED, hospital)?
- Do our research procedures influence dyadic selection, experience, and outcomes? Are we adding further confounding?

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Photos, courtesy of <https://www.pexels.com>

Care of PLWD with Multiple Chronic Conditions

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 - NIH (NIA)
 - PCORI
 - AAHQI: Alliance for Home Health Quality and Innovation
 - I co-author a chapter for UptoDate on multiple chronic conditions.

What do we know?

- Most people living with dementia also suffer from chronic medical or mental health conditions
- These conditions may explain most excess health care costs and utilization
- These conditions may also play a major role in quality of life, functional capacity, and reversible disability.

Harrison et al. J Am Geriatr Soc 2019 Sep;67(9):1907-1912. doi: 10.1111/jgs.16054. Epub 2019 Aug 7

<https://www.alz.org/media/Documents/chronic-care-r.pdf>

“Treating an Illness Is One Thing. What About a Patient With Many?”



New York Times, March 31, 2009

Image: Brendan Smialowski for the New York
Times

It's Not Easy Living with Multiple Chronic Conditions

Time	Medications	Non-pharmacologic Therapy	All Day	Periodic
7 AM	Ipratropium MDI Alendronate 70mg weekly	Check feet Sit upright 30 min. Check blood sugar	Joint protection Energy conservation	Pneumonia vaccine, Yearly influenza vaccine
8 AM	Eat Breakfast HCTZ 12.5 mg Lisinopril 40mg Glyburide 10 mg ECASA 81 mg Metformin 850mg Naproxen 250mg Omeprazole 20mg Calcium + Vit D 500mg	2.4gm Na, 90mm K, Adequate Mg, ↓ cholesterol & saturated fat, medical nutrition therapy for diabetes, DASH	Exercise (non-weight bearing if severe foot disease, weight bearing for osteoporosis) Muscle strengthening exercises, Aerobic Exercise ROM exercises	All provider visits: Evaluate Self-monitoring blood glucose, foot exam and BP Quarterly HbA1c, biannual LFTs Yearly creatinine, electrolytes, microalbuminuria, cholesterol <u>Referrals:</u> Pulmonary rehabilitation Physical Therapy DEXA scan every 2 years Yearly eye exam
12 PM	Eat Lunch Ipratropium MDI Calcium+ Vit D 500 mg	Diet as above	Avoid environmental exposures that might exacerbate COPD Wear appropriate footwear	Medical nutrition therapy <u>Patient Education:</u> High-risk foot conditions, foot care, foot wear Osteoarthritis COPD medication and delivery system training Diabetes Mellitus
5 PM	Eat Dinner	Diet as above	Albuterol MDI prn Limit Alcohol Maintain normal body weight	
7 PM	Ipratropium MDI Metformin 850mg Naproxen 250mg Calcium 500mg Lovastatin 40mg			
11 PM	Ipratropium MDI			

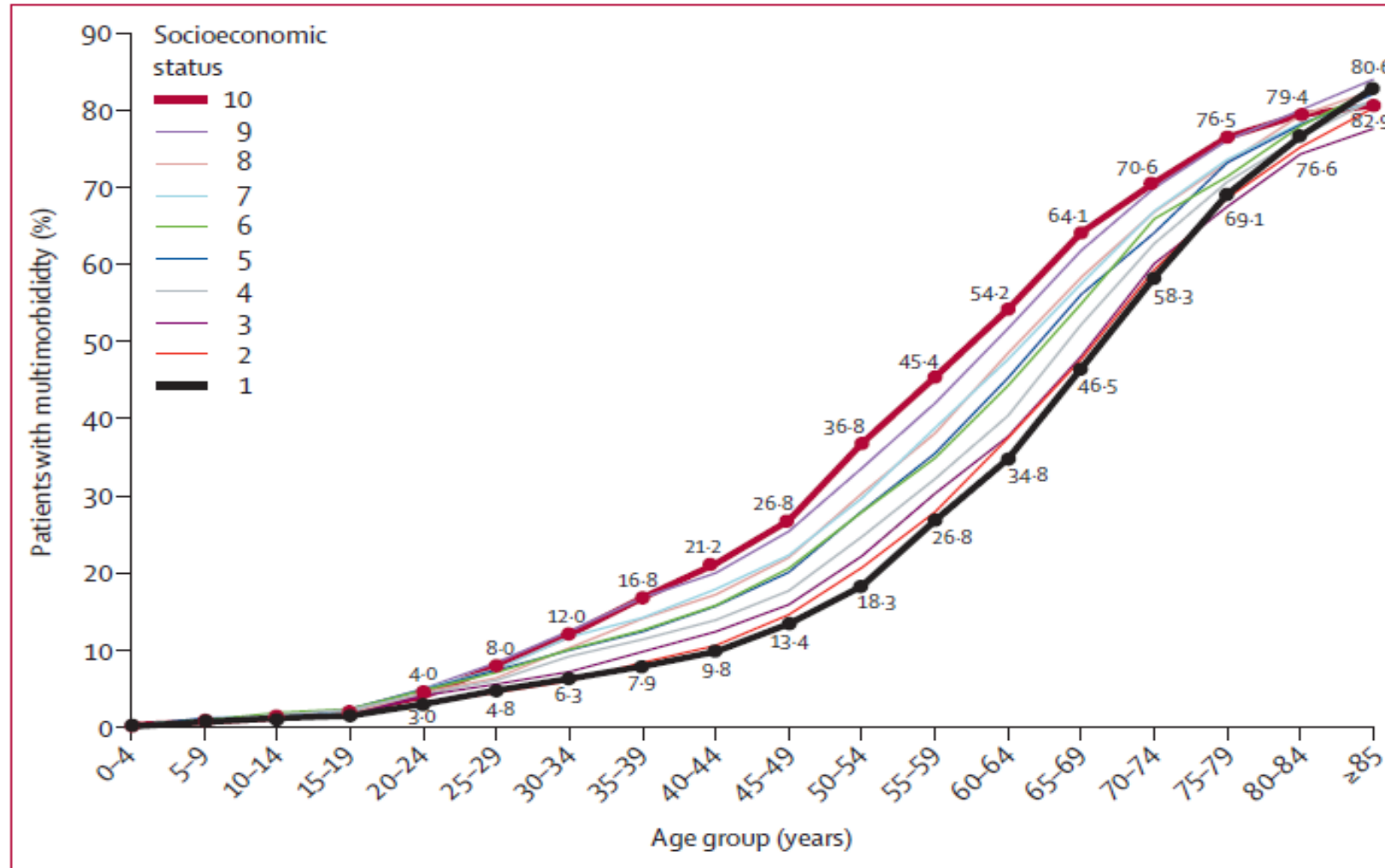
What if this person also lived with dementia?

Time	Medications	Non-pharmacologic Therapy	All Day	Periodic
7 AM	Ipratropium MDI Alendronate 70mg weekly	Check feet Sit upright 30 min. Check blood sugar	Joint protection Energy conservation	Pneumonia vaccine, Yearly influenza vaccine All provider visits: Evaluate Self-monitoring blood glucose, foot exam and BP Quarterly HbA1c, biannual LFTs Yearly creatinine, electrolytes, microalbuminuria, cholesterol <u>Referrals:</u> Pulmonary rehabilitation Physical Therapy DEXA scan every 2 years Yearly eye exam Medical nutrition therapy <u>Patient Education:</u> High-risk foot conditions, foot care, foot wear Osteoarthritis COPD medication and delivery system training Diabetes Mellitus
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11 PM	Ipratropium MDI			

How common is it to live with dementia and multiple other chronic conditions?

- People living with dementia in the community:
Have an average of 3.2 other chronic conditions
- Out of 10 other conditions
Heart attack, heart disease, high blood pressure, arthritis, osteoporosis, diabetes, lung disease, stroke, cancer, hip fracture.
- Nationally representative data from National Health and Aging Trend Survey
- Even higher among people living with dementia in long-term care

Prevalence of multiple chronic conditions (including dementia) as a function of age, stratifying on socio-economic status



On socioeconomic status scale, 1=most affluent and 10=most deprived." From Barnett et al, Lancet 2012, 380(9836): 37-43

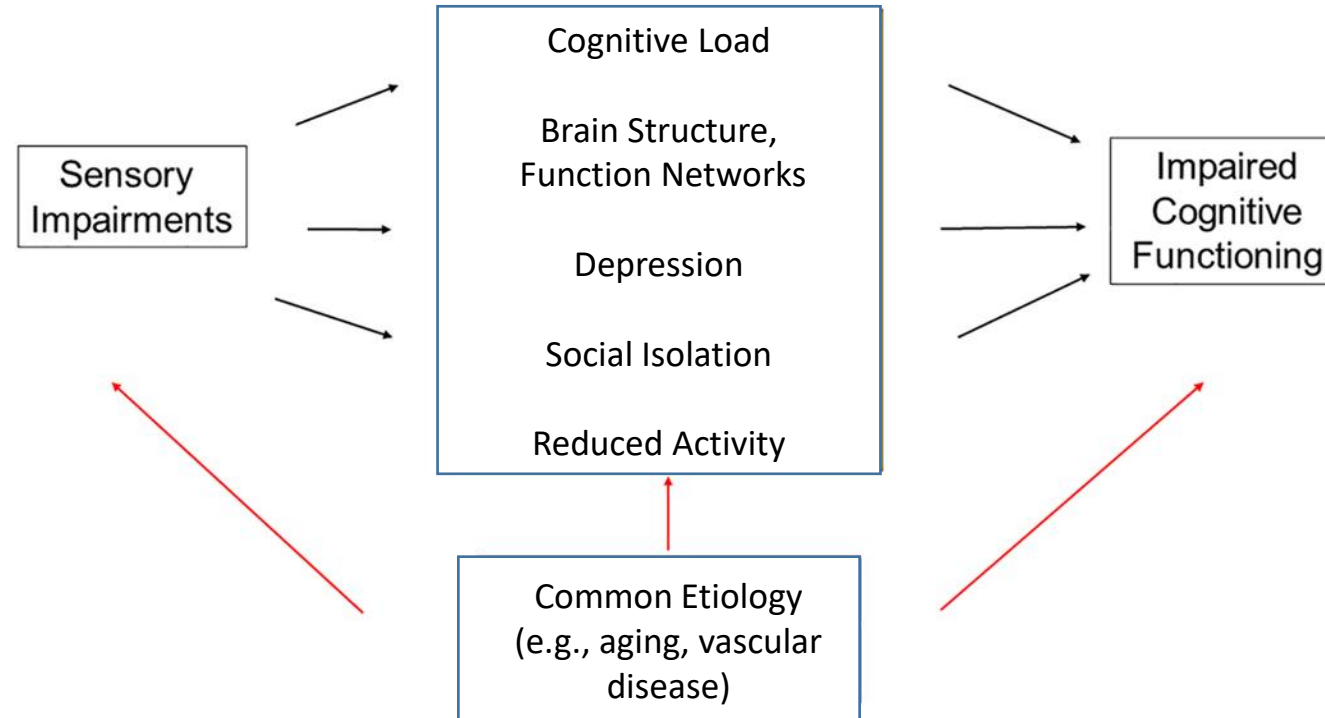
Dementia plus Multiple Chronic Conditions Disproportionately Impact Priority Populations

African Americans and Hispanics more likely to suffer from dementia than Whites and spend more years living with dementia.

Socially disadvantaged groups more likely to have multiple chronic conditions and poorer health.

Priority Populations are at risk for both under- and over-prescribing and under- and over-treatment. Little known about rates of medication and intervention use in these populations.

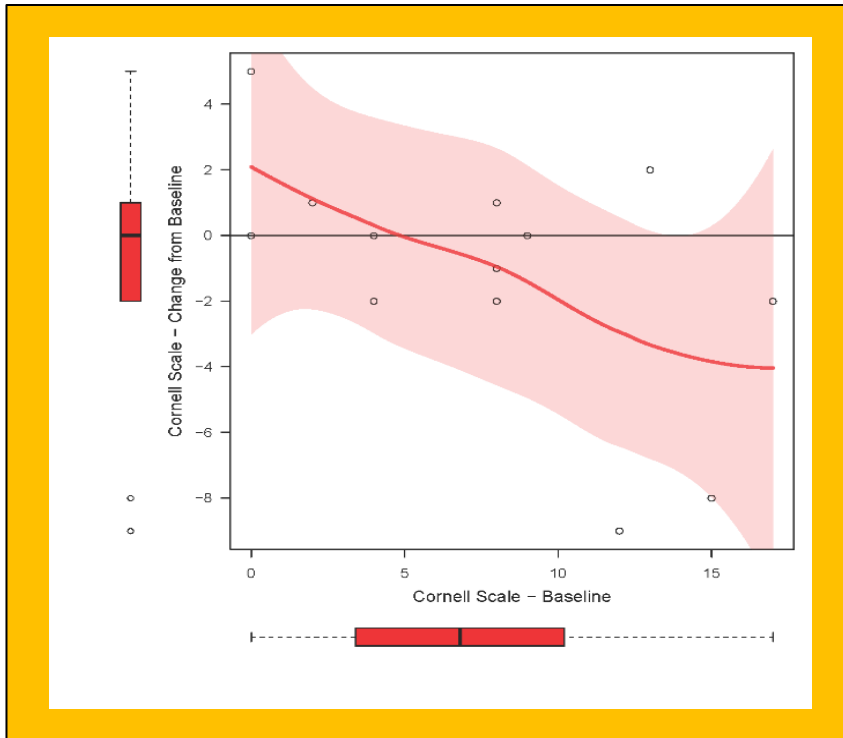
Promising Opportunities: Targeting Sensory Impairments and Dementia



Journal of the American Geriatrics Society, Volume: 66, Issue: 11, Pages: 2052-2058, First published: 24 September 2018, DOI: (10.1111/jgs.15506)

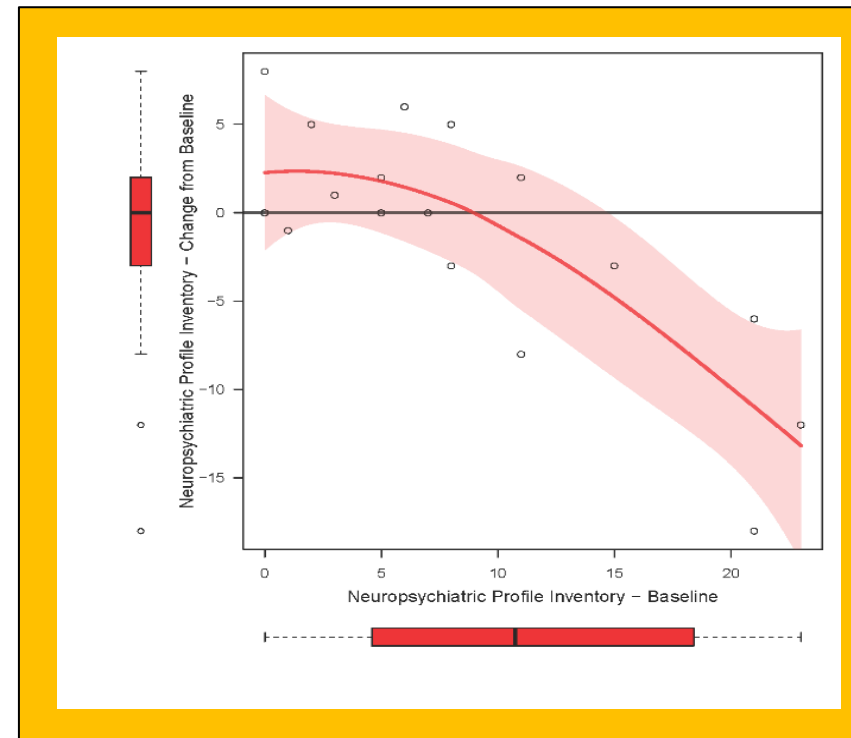
Hearing Intervention at 1 Month

Depression



Greater improvement of depression in those with worse depression at baseline

Neuropsychiatric Symptoms



Greater improvement of NPS in those with worse NPS at baseline

Overarching themes that inform decision making for people living with dementia and multiple chronic conditions and care partners

Balancing the risks and benefits of treatment options

You weigh [the options]. And you figure, is it good for me to do it at this particular time? or later? And the result is I am always going to do what I think is best for me. Regardless of what the doctor says. Because he doesn't have my body. He assumes I have this type of pain but does he know what I am feeling?

What is health, well-being to you

“Just feeling well, at peace with yourself, perhaps for a while not dwelling on problems, and you get some period of comfort. It is just joy. And I love it.”

Individualizing clinical recommendations to “match” each unique person

[T]he beta blocker,...was like somebody sitting on my chest 24 hours a day. But it was helping my heart at the same time. But I just could not function. So we changed. [My doctor] said OK, we'll work in another way...but I said no more of them, because ...then they found out I had COPD and that's why I was going around sounding like a horse, you know?

Coping with memory problems, participating in daily activities, maintaining abilities

“I don't want to lose memory, sometimes I have something like memory loss, and I think that interventions like this one can be useful for my memory”

What don't we know that we should?

- How to implement effective dementia + multiple chronic condition care programs in our current, diverse health system
- What are the best approaches to effectively address health care needs in holistic ways for PLWD (interventions – learnings from a robust body of literature)
- How to get the entire health care system prepared for and accepting of a population of PLWD and multiple chronic conditions and care partners
- How to best treat many other chronic conditions in the presence of dementia

Reilly et al. Cochrane review <https://doi.org/10.1002/14651858.CD008345.pub2>

Snowden et al. Int J Geriatr Psychiatry 2017 Apr;32(4):357-371. doi: 10.1002/gps.4652. Epub 2017 Feb 1.

What Do Clinicians Need to Best Care for People Living with Dementia and Multiple Chronic Conditions?

- Maximize use of therapies likely to benefit PLWD with multiple chronic conditions
- Minimize use of therapies unlikely to benefit or likely to harm PLWD with multiple chronic conditions
- Incorporate patient and family preferences and values regarding burdens, risks, and benefits
 - *Most decisions are preference sensitive*
 - *Different people and their care partners will make different decisions, even with the same information*

We have some evidence to guide us in this, but there is much more that we don't know.

What are promising opportunities for future research?

- Addressing opportunities for undertreatment and overtreatment in people living with dementia and multiple chronic conditions
 - Sometimes symptoms will improve with deprescribing of unnecessary or harmful medications
 - Sometimes symptoms are undertreated in PLWD (e.g. pain)
- Designing/Adapting strategies for the management of chronic conditions for PLWD
 - For example, PLWD often have urinary incontinence. Many bladder control medicines may worsen cognition and other issues, especially in PLWD. But we don't have effective, let alone widely available, strategies to use a non-pharmacological approach to help PLWD and their families manage urinary incontinence.
- Determining effective and implementable strategies for person- and family centered care, based on goals, for PLWD

Clinical decision making: Includes prescribing and deprescribing

• Continuation



• Discontinuation

- Weigh the risk and benefits of discontinuing the medication equally against the risks and benefits of continuing the medication
- Deciding to continue the medication is still an active decision
- Ethically and legally same responsibility for benefits and harms for both continuation and discontinuation (e.g. continuing a falls risk medication and the patient having a fall)

Multiple Chronic Conditions in Context, PLWD

Moving from “What is the matter?” to “***What Matters to You?***”

Key contextual factors: public policy, community, health care systems, family, and person, to sub-personal cellular and molecular levels (where most medical knowledge currently is generated)

New knowledge needed involves moving from a predominant disease focus toward a person-driven, goal-directed research agenda

NIH/PCORI Meeting on Multiple Chronic Conditions in Context, Feb. 2013

Bayliss et al Ann Fam Med. 2014 May-Jun;12(3):260-9. doi: 10.1370/afm.1643.

Comprehensive Dementia Care Program

- Co-managed by nurse practitioners and physicians
- structured needs assessments of PLWD and their care partners,
- creation and implementation of individualized dementia care plans with input from primary care physicians,
- monitoring and revising care plans,
- referral to community organizations for dementia-related services and support, and access to a clinician for assistance and advice 24 hours per day, 7 days per week.

Example Goal related to
Multiple Chronic

Conditions:

Desire less burdensome care, fewer health care visits, less pain

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- Green et al. J Gen Intern Med. 2020 Jan;35(1):237-246. doi: 10.1007/s11606-019-05424-6. Epub 2019 Nov 8
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- Bayliss et al Ann Fam Med. 2014 May-Jun;12(3):260-9. doi: 10.1370/afm.1643

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Financing the care of PLWD

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Disclosures

- My recent work has been funded by:
 - NIH (NIA and NINR)
 - AARP Foundation
 - Robert Wood Johnson Foundation
 - The Health Care Authority of the state of Washington
 - Donahue Foundation

What do we know?

- Care for PLWD is largely uninsured.
 - Medicare does not cover long-term services and supports; unfortunately little acute care is available for dementia.
 - Private long-term care insurance has minimal coverage (<15% of people > 65); market is shrinking.
 - Medicaid will step in once private resources are drained.
 - Major payer for long-term care in the US.
 - Spends more now on home and community based services than nursing homes.

What do we know?

- Care for PLWD is expensive (all in 2017 dollars).
 - Annual costs to Medicare range from \$3,019 to \$10,598.^{4,11,16,21}
 - Annual costs to Medicaid range from \$5,698³ to \$7,824.²²
 - Annual average out of pocket costs to families range from \$9,236⁸ to \$13,831.¹³
 - Annual costs of caregiving range from \$27,647¹⁴ to \$56,000.¹⁵
- In total: Annual cost estimates range from \$46,863 to \$63,276.¹¹
- Lifetime costs: \$332,780.¹²
- Annual nationwide cost estimates range from \$242 billion¹¹ – \$278 billion.²

2. Alzheimer's Association, 2019

3. Ayyagari, 2007

4. Bynum, 2004

8. Delavande, 2013

11. Hurd, 2013

12. Jutkowitz, 2017

13. Kelley, 2015

14. Moore, 2001

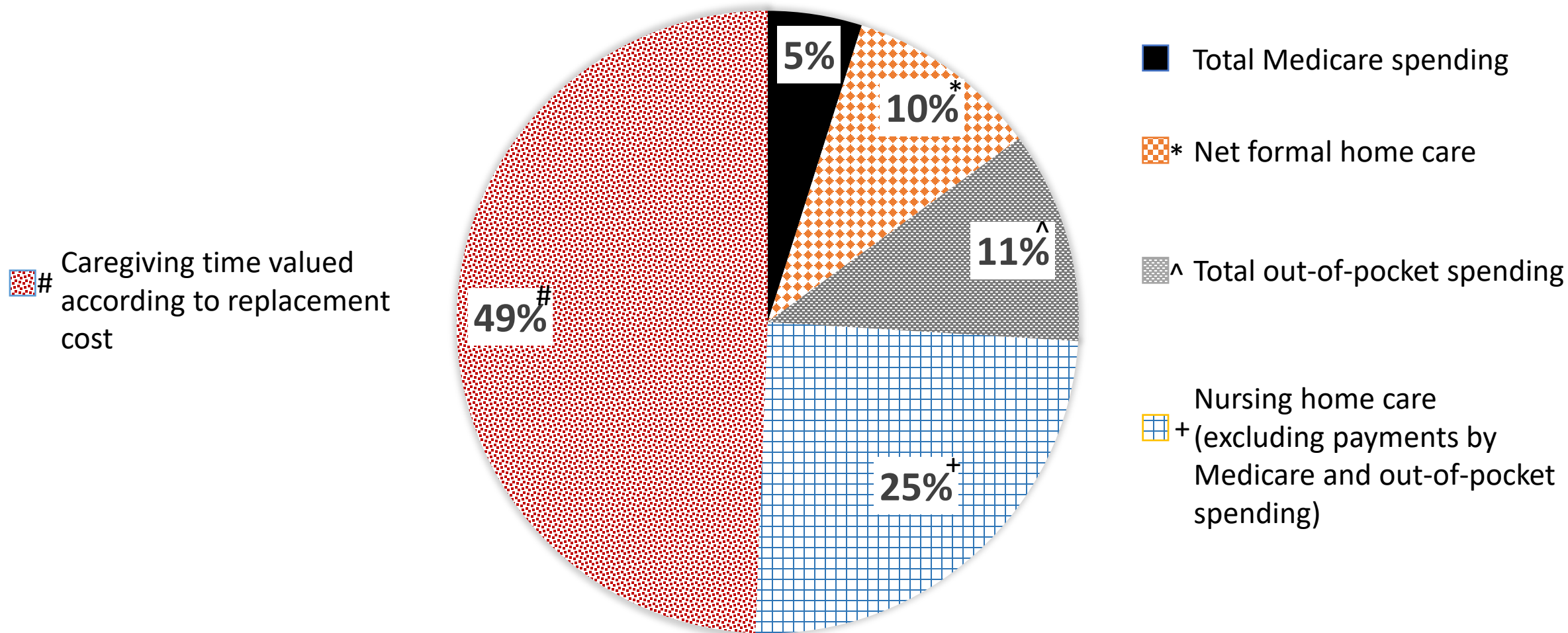
15. National Alliance for Caregiving
and the Alzheimer's Association, 2017

16. Oney, 2019

21. Weiner, 1998

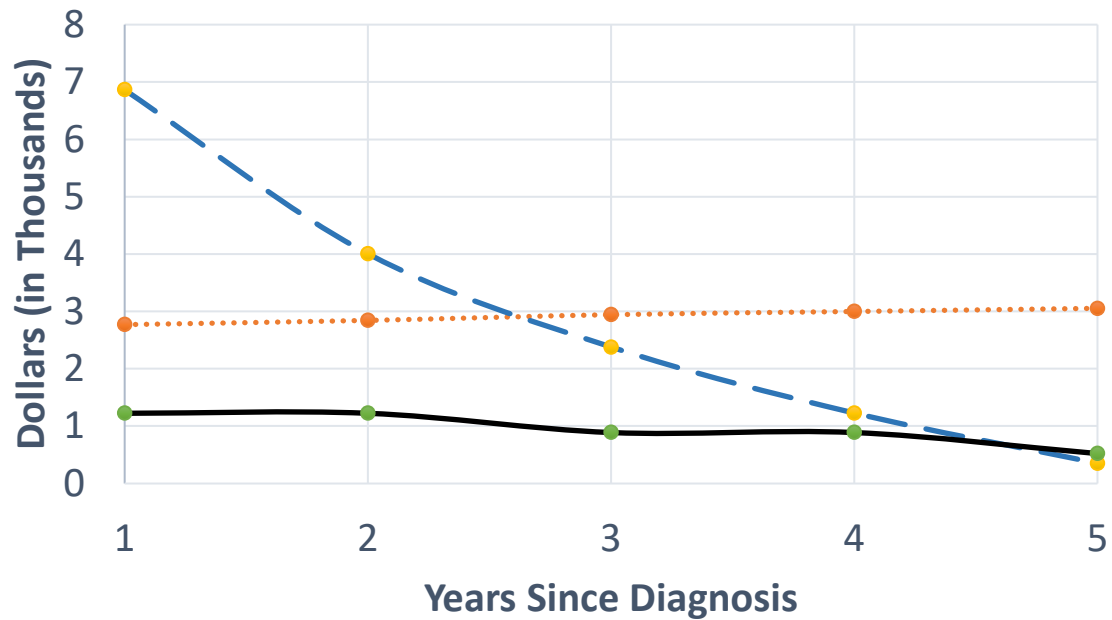
22. Yang, 2012

Cost break-down of prevalent dementia cases¹¹

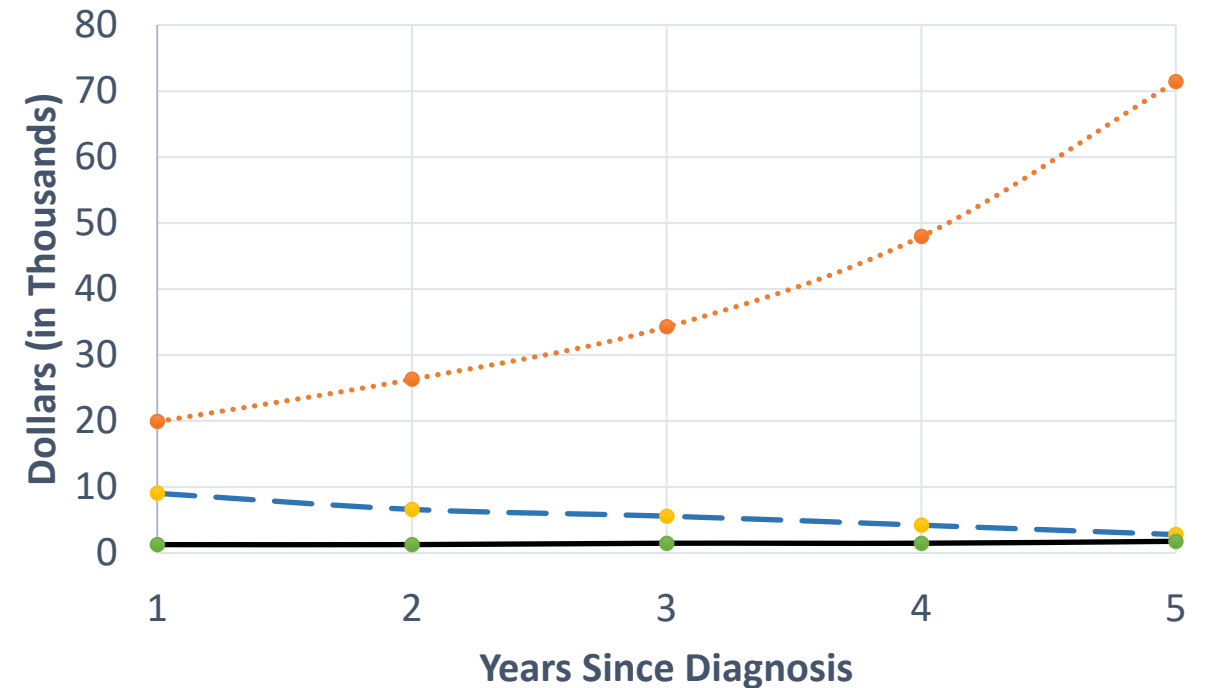


Time trends for incident cases of dementia^{7,16}

Cohort as a Whole



Conditional on Being Alive and Enrolled



.....○ Medicaid - - - ● Medicare — ● OOP

What do we know? Caregivers

- Costs to caregivers is more than a lost hourly wage.
 - Caregiving takes a toll on ones' health – increased rates of depression and anxiety,¹⁷ increases in physical injuries,⁹ worse short-term health,⁶ and more psychotropic drug use.²⁰
- As the needs increase, you need more flexibility at work, wages stagnate or decline, which impacts your income today *and* lowers your future earnings.
 - Female caregivers experience a wage penalty of around \$0.66 per hour.¹⁹
- If you're a woman in your late 50 or early 60's trying to re-enter the labor market, **3%** will get a full-time offer, and **15%** will get a part-time offer.⁵

5. Coe, 2018

6. Coe, 2009

9. Haley, 1987

17. Schulz, 1995

19. Van Houtven, 2013

20. Van Houtven, 2006

What do we know? Caregivers

- With a more comprehensive model that also accounts for lost leisure time and changes to the caregiver's well-being:⁵
 - Median direct and indirect costs of caregiving are \$180,000 over two years.
 - When the mother cannot be left alone for more than 1 hour, the costs rise to more than \$200,000 over 2 years.
 - At least 20 percent higher than estimates that only consider lost wages.
- Dwarfs the direct health care costs to any insurance program.

What do we know? Disparities

- Combined Medicare and Medicaid costs for blacks with dementia are about 28%¹² higher than for non-blacks with dementia.
- Out of pocket costs for whites with dementia are higher than for racial minorities with dementia, with a difference of \$11,283 over the first 8 years.¹⁶
- Women with dementia cost, on average, 14%¹³ more than men with dementia during the last 5 years (Medicare, Medicaid, OOP, and caregiving costs).

12. Jutkowitz, 2017

13. Kelley, 2015

16. Oney, 2019

What do we need to know?

- We don't know how financing/having insurance changes utilization and outcomes.
 - Better idea of care trajectories, and how finances influence these choices.
 - We don't know what is the best care money can buy.
- We don't know how well Medicare and Medicaid work together in providing person-centered care for PLWD.
 - > 25% of PLWD are dual-eligible, compared to 11% in population as a whole.¹
 - Mixed evidence on cost-effectiveness of PACE.¹⁰
 - Increased or decreased coordination costs for caregiver?
 - Change the location of care?

1. Alzheimer's Association, 2017

10. Gonzalez, 2017

What do we need to know?

- We don't know how much the financing model is hindering adoption of innovative care models or technology, or how best to leverage experimentation.
- We don't know how wide-spread early detection could be funded, or what implications it would have on individuals, families, utilization, and costs, to know if it is or could be cost-effective.

What do we need to know?

- We are building an evidence-base on how to improve caregiver outcomes, but don't have widespread evidence of cost-effectiveness or a plan for how to pay for broad access.
 - Does having a caregiver decrease costs? And could those offsets could be used to support caregivers directly and still have a financial or health gain?
- We don't know how changing the financing system to a more universal coverage system would change utilization, costs, outcomes, or the economy.

Promising Avenues for Future Research

- Medicaid – LTSS experimentation and variation to learn from.
- The VA System leading the way with experimentation for caregiver support; lots to learn.
- New data resources on alternative care settings (assisted living, memory care, CCRCs) to allow more settings to be studied.
- NIH Collaboratory's focus on *pragmatic* clinical trials and rapid execution.

What do we need?

- Timelier data from Medicare, Medicaid, and Medicare Advantage, and linkages across the systems.
- Easier access to VA data and Medicare Advantage data.
- More system/clinician-level data on training & practices, linkable to outcome data.
- Continued efforts linking survey and claims data, in order to link caregivers, care recipients, care providers, outcomes and costs.

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Theme 3: Research Opportunity 1

Evaluate and compare comprehensive models of care and develop new models for subgroups of persons living with dementia that are not effectively served by existing models. Specifically compare “stand-alone” care models that support primary care of PLWD/dyads versus embedded primary care programs.

Theme 3: Research Opportunity 2

Determine the core competencies, domains, and milestones needed to ensure that care for PLWD is consistent with evidence based clinical standards, that is, care that maximizes function and quality of life across the continuum of health professionals who care for PLWD

Theme 3: Research Opportunity 3

Develop and test relative efficiency and effectiveness of strategies to provide persons living with dementia and their family caregivers with diagnostic and longitudinal care for all their health care needs, including co-existing conditions, in various settings including typical clinical settings such as ambulatory care network settings and small practice settings, settings serving PLWD who have limited resources, including rural and safety net settings (such as Federally-Qualified Health Centers), and residential care

Theme 3: Research Opportunity 4

Assess the impact of promoting early stage care planning, assessment, evaluation of preferences, and advanced care coordination - including advance care planning, end-of-life, palliative care, and hospice on efficiency, effectiveness and experience of care

Theme 3: Research Opportunity 5

Evaluate and compare comprehensive models of care and develop new models for subgroups of persons living with dementia that are not effectively served by existing models. Specifically compare “stand-alone” care models that support primary care of PLWD/dyads versus embedded primary care programs.

Theme 3: Research Opportunity 6

Determine the qualitative and quantitative impact of improvements in detection, diagnosis, treatment and care management of PLWD, including the ability of health care providers across all treatment settings, on individuals, families, and society.

Theme 3: Research Opportunity 7

Study the effect of access to health insurance on the receipt of person-centered care and the location of care for PLWD

Theme 3: Research Opportunity 8

Determine how payment affects access and quality of care received by people with dementia in a variety of community and residential settings

Theme 3: Research Opportunity 9

Develop and test the ethical implications and cost-effectiveness of inclusion of the caregiver in the care team of the PLWD