



Theme 1

Impact of Dementia



María P. Aranda, PhD
Ian Kremer, JD
Co-Chairs, Theme 1

March 24-25, 2020

Theme 1: Impact of Dementia

This theme includes issues related to heterogeneity and trends in the lived experience of dementia, including the clinical impact and trajectory for people living with dementia and their family caregivers across the range of etiologies; the economic impact of dementia for patients, caregivers, payers, public programs, and society; and the effects of dementia, including the impact of health disparities on diverse populations – for example by sex and gender, socioeconomic status, geography, race and ethnicity, language, education, living arrangements, including people living alone or without caregivers.



Population Trends of ADRD: Importance of Lifecourse and Diversity

Rachel Whitmer, PhD
Professor and Chief of Epidemiology
Associate Director, Alzheimer's Disease Center
University of California , Davis



@Prof_R_Whitmer
<https://rachelwhitmer.ucdavis.edu>

March 24-25, 2020

Disclosures

NIA RF1AG056519 (Whitmer PI)

NIA R01AG050782 (Whitmer PI)

NIARF1AG052132 (Whitmer PI)

NIA R01AG047500 (Whitmer PI)

I receive funding from the Alzheimer's Association

USPOINTER Northern California (Whitmer PI)

Key Points: Cross Cutting Theme Disparities

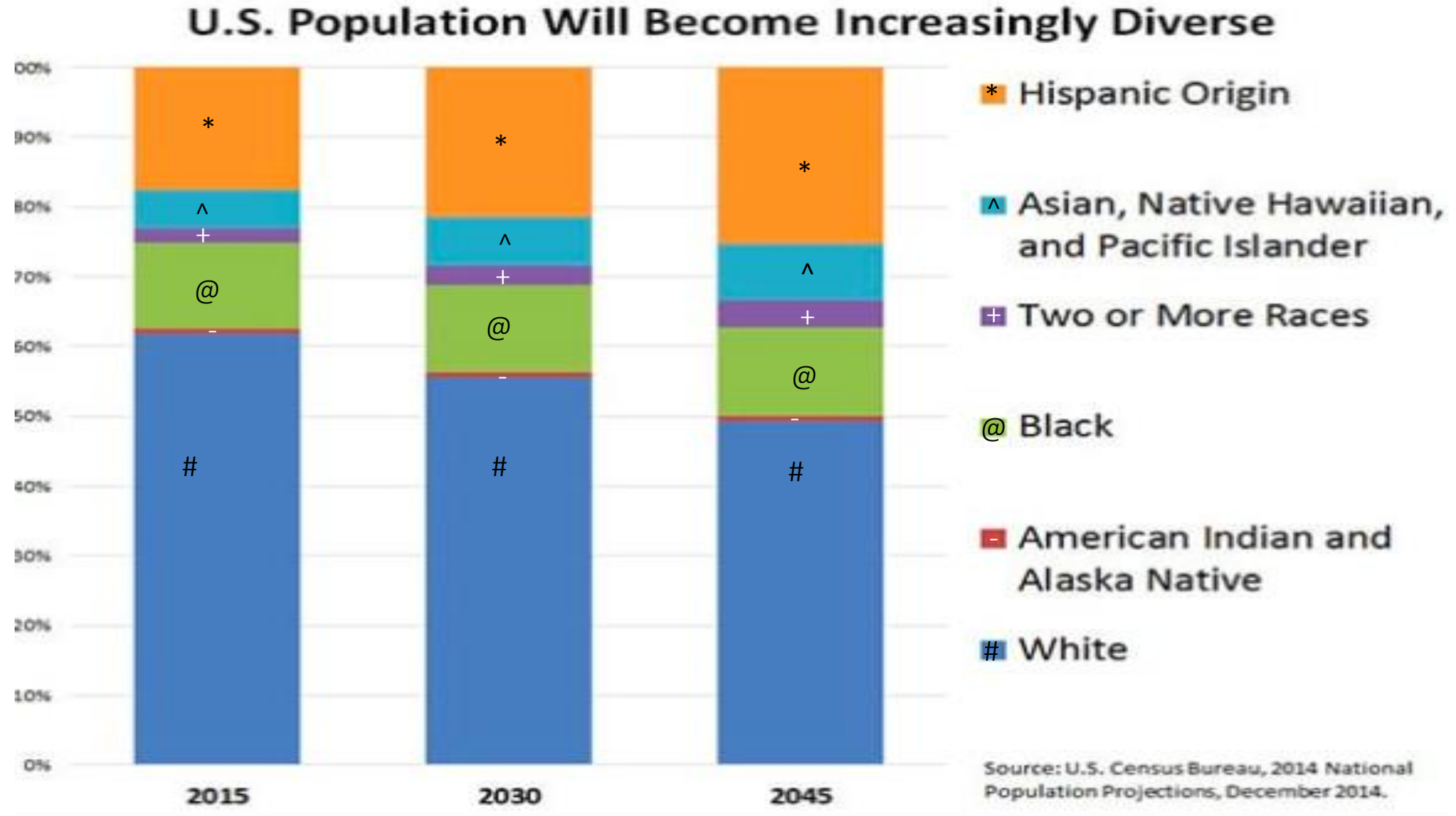
- Epidemiological patterns in rates of ADRD by racial and ethnic group
- Which groups are still missing from ADRD population research?
- Disparities in rates of ADRD and risk factors for ADRD
- Risk factors operate differently at different time points in different populations
- Lifecourse approach to ADRD population research is essential to reduce disparities
- Harmonization and methods tool box must be used

Why do we care about Population Trends in ADRD?

- Do we really need to keep counting ?
- study and analysis of the distribution and determinants of health and disease conditions in defined populations
- the branch of medicine that deals with the incidence, distribution, and **possible control** of diseases and other factors relating to health.

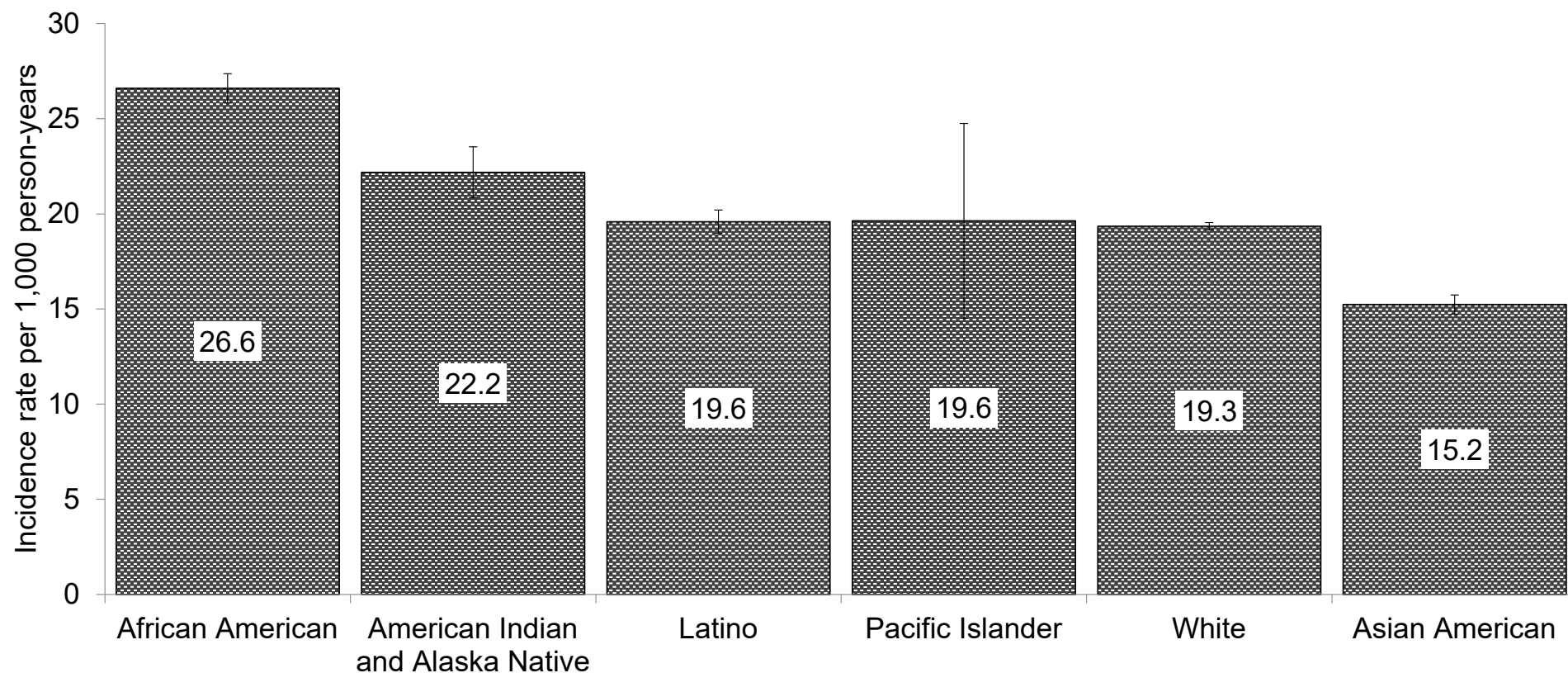


Why is Diversity Important in Population Studies of ADRD?



Studies need to Represent the FUTURE of the
population

Inequalities in dementia incidence between six racial and ethnic groups over 14 years in 274,000 health plan members



Inequalities in dementia incidence between six racial and ethnic groups over 14 years. Alzheimers Dement. 2016 Feb 10. Mayeda ER et al 2016

Cumulative Incidence of Dementia after Age 90 in Four Racial/Ethnic Groups

Gilsanz P, et al 2018, Alz & Associated Disorders

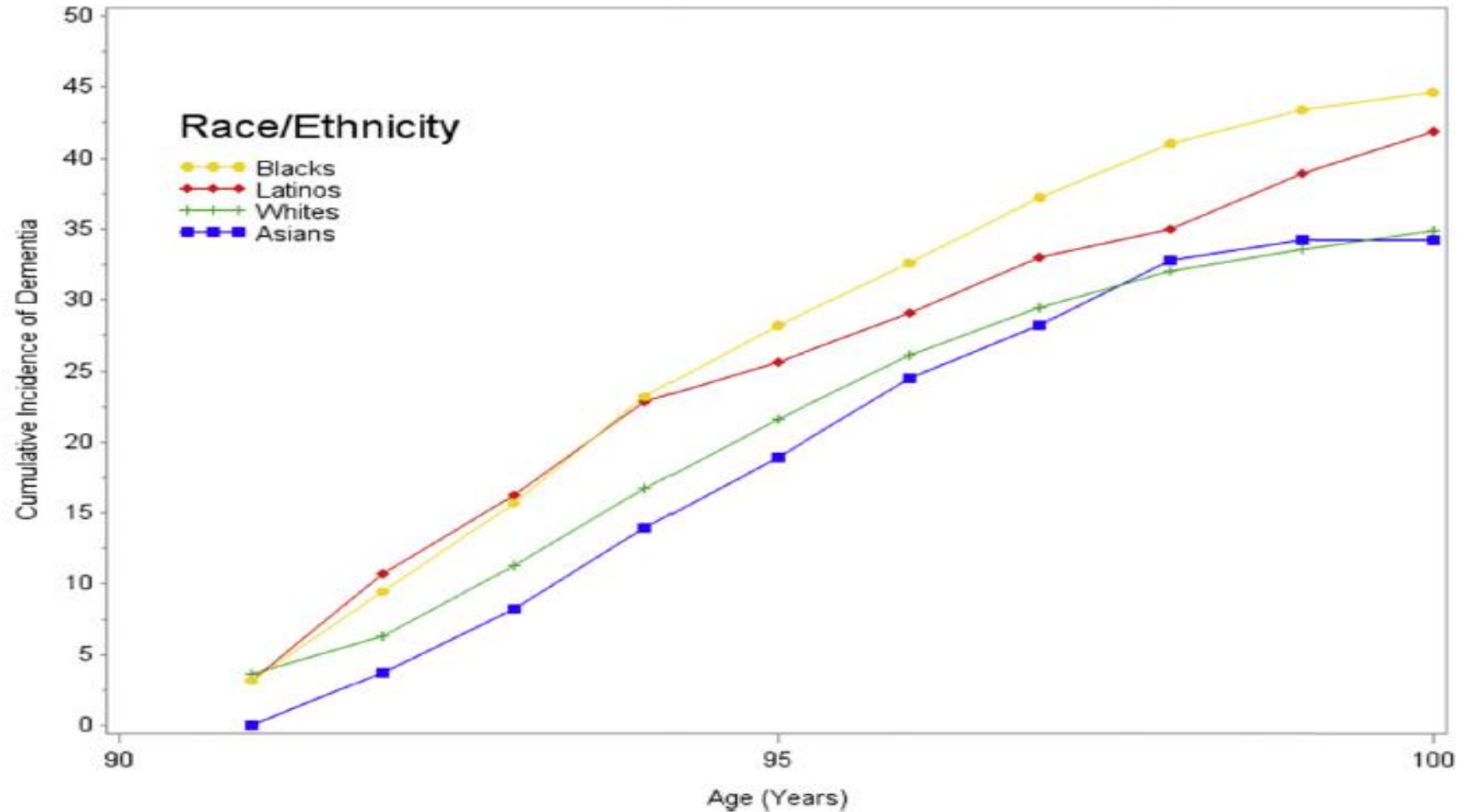


Fig. 1. Cumulative incidence of dementia conditional on survival until the age of 90 years by race/ethnicity conditional on survival without dementia until the age of 90 and accounting for competing risk of death.

Race and Risk of Dementia in those with Type 2 Diabetes

Table 2—Dementia incidence densities by race/ethnicity (1998–2007)

Race/ethnicity	<i>n</i>	Cases	Cumulative incidence (%)	Person-years	Age-adjusted incidence density* (95% CI)
Non-Hispanic white	14,546	2,586	17.78	93,893.03	25.33 (24.28, 26.37)
African American	2,484	475	19.12	17,374.39	26.70 (24.20, 29.20)
Latino	2,363	354	14.98	17,365.58	24.33 (21.29, 27.38)
Asian	2,262	283	12.51	17,072.08	19.17 (16.60, 21.74)
Native American	516	98	18.99	3,165.83	33.94 (26.69, 41.19)

*Per 1,000 person-years, using 2000 U.S. Census as the standard.

Patterning of Dementia rates by racial/ethnic group is the same in the context of type 2 diabetes and after age 90 in members of a health care delivery system

Mayeda ER et al 2015

Why does it matter if rates of AD/DRD differ in different populations ?

- **Magnitudes different ; implications for impact of population source**
- **Initial look at certain groups; American Indians/ Asian Americans**
- **Equal access to healthcare**
- ***Reducing dementia rates in all racial/ethnic groups to the rates observed among Asian Americans would prevent over 190,000 dementia cases annually in the United States and have a major public health impact.***
- **Clues of where to look more closely**

Why is Heterogeneity in Population Studies of ADRD Important for Dementia Care ?



Is Education and Treatment of Cardiovascular Risk Factors Favorably Impacting Rates of Dementia ?

N Engl J Med. 2016 February 11; 374(6): 523–532. doi:10.1056/NEJMoa1504327.

Incidence of Dementia over Three Decades in the Framingham Heart Study

Claudia L. Satizabal, Ph.D., Alexa S. Beiser, Ph.D., Vincent Chouraki, M.D., Ph.D., Geneviève Chêne, M.D., Ph.D., Carole Dufouil, Ph.D., and Sudha Seshadri, M.D.

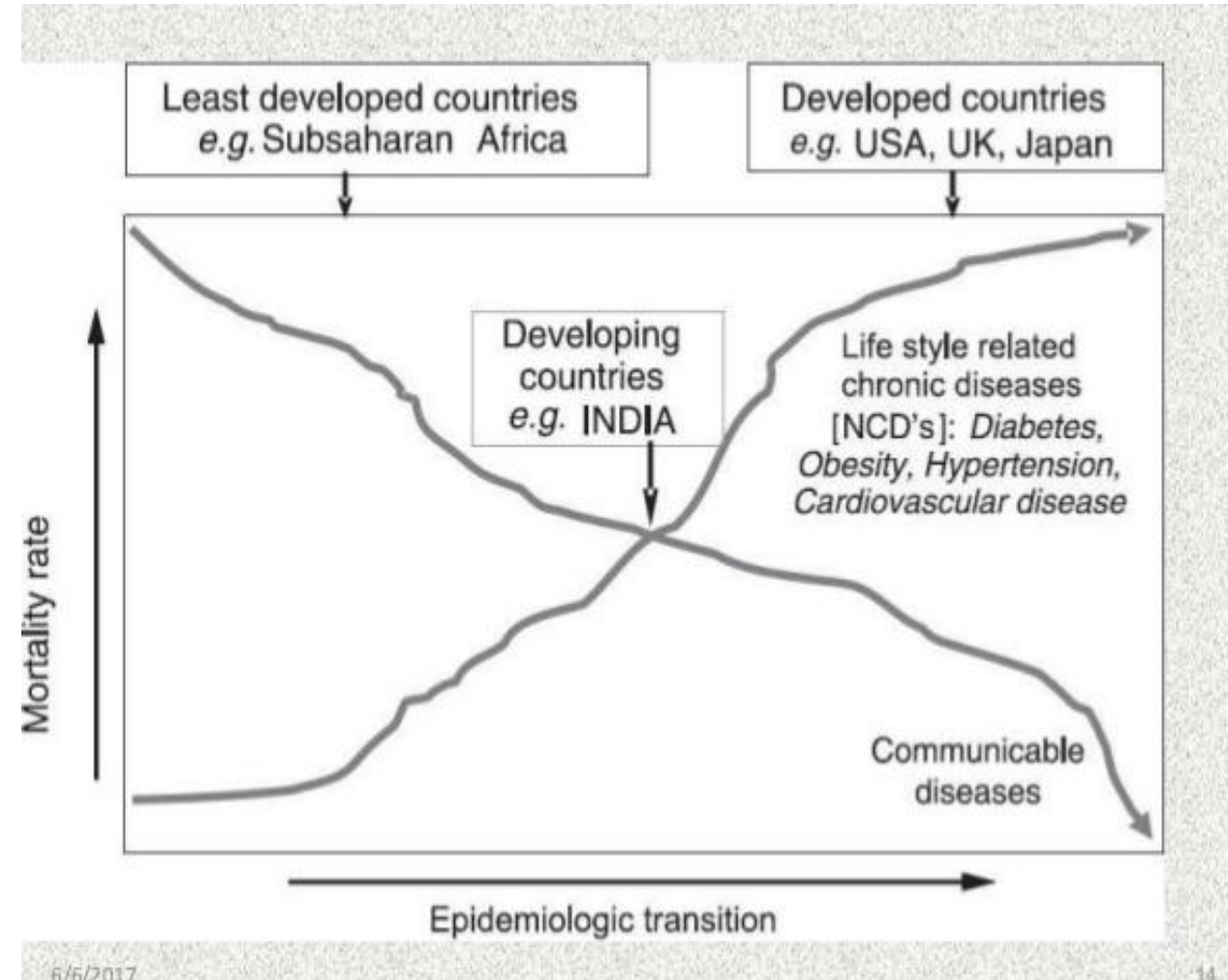
WHO we study and HOW we study them matters

What can we uncover about dementia by studying populations and *changes* in populations

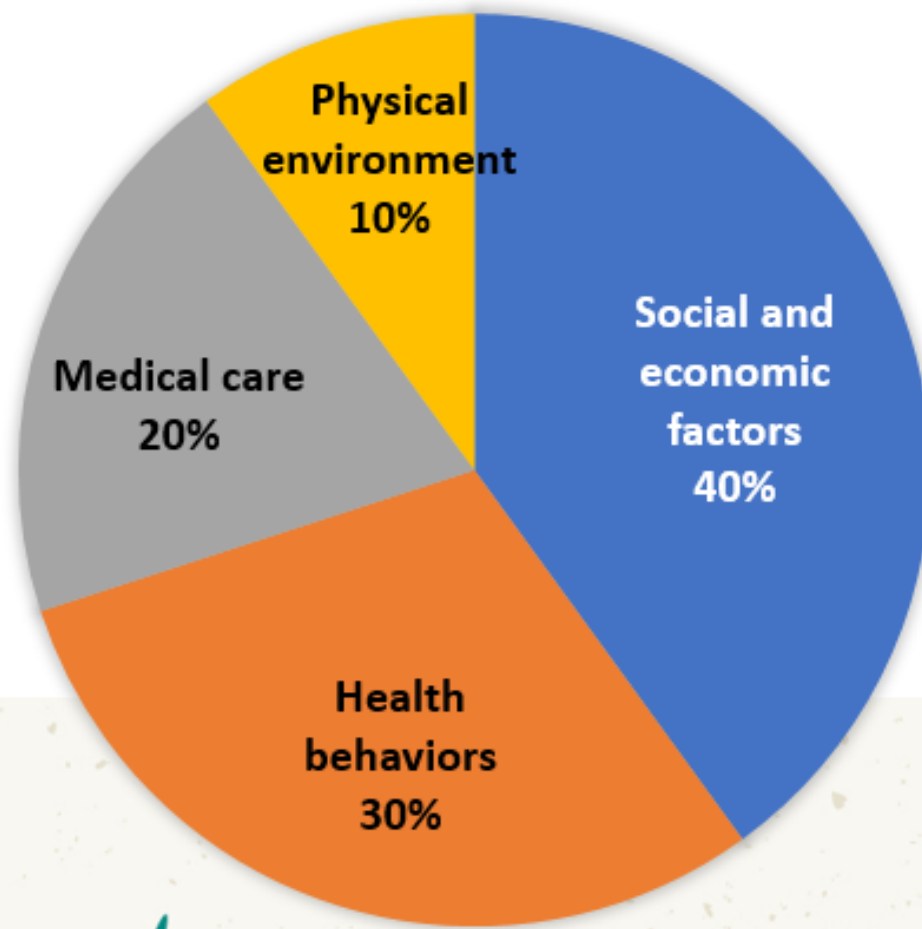
- Rapidly changing burden of chronic disease
- Changes in prevalence, screening treatment of RISK Factors

Accelerated aging and different mortality rates by race/ethnic group

- To inform CARE we need to evaluate the right populations !



Social Determinants of Health & Health Disparities



The “unequal distribution of health-damaging experiences is not in any sense a ‘natural’ phenomenon but is the result of a toxic combination of poor social policies and programmes, unfair economic arrangements, and bad politics.”

- WHO Commission on Social Determinants of Health, 2008



Social Context and Race: Place of birth has enduring consequences on risk of dementia

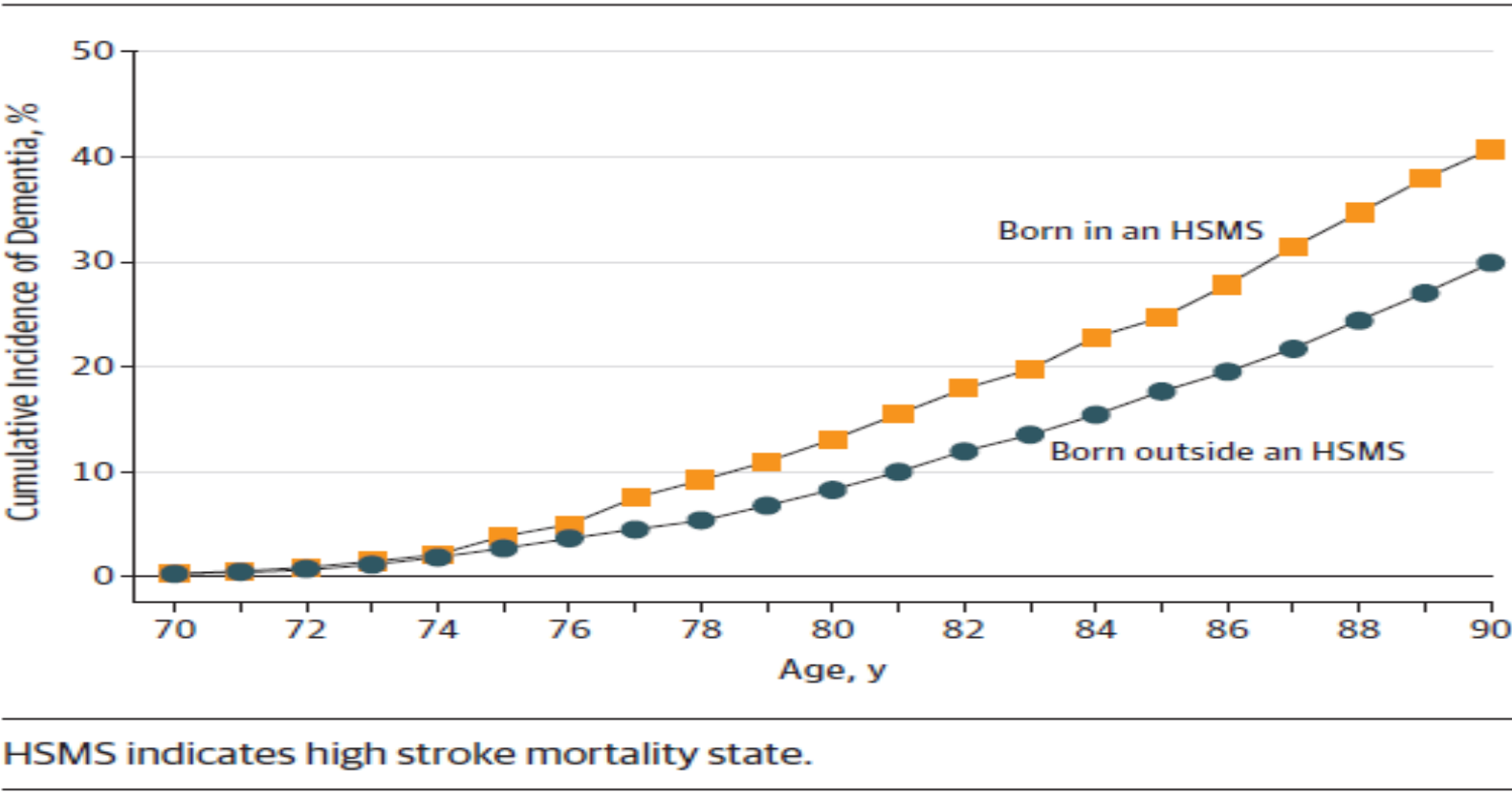
	Born outside a high stroke mortality state		Born in a high stroke mortality state	
	White	Black HR (95% CI)	White HR (95% CI)	Black HR (95% CI)
Age, sex, education and mid-and late-life cardiovascular risk	Ref	1.32 (1.13-1.54)	1.43 (1.20-1.70)	1.48 (1.31-1.68)

Midlife vascular risk factors are body mass index, smoking duration, and hypertension status. Late life cardiovascular risk includes diabetes, hypertension, heart failure, acute myocardial infarction, and stroke.

Gilsanz P, et al, JAMA: Neurology 2017

Stroke belt birth and cumulative incidence of dementia

Figure. Cumulative Incidence Dementia Adjusted for Death Rates by Birth Place



Birth in a high stroke mortality state was 9.6 times more common for Black participants; (58.7% of Blacks were born in high stroke mortality state versus 6.1% for non-Black)

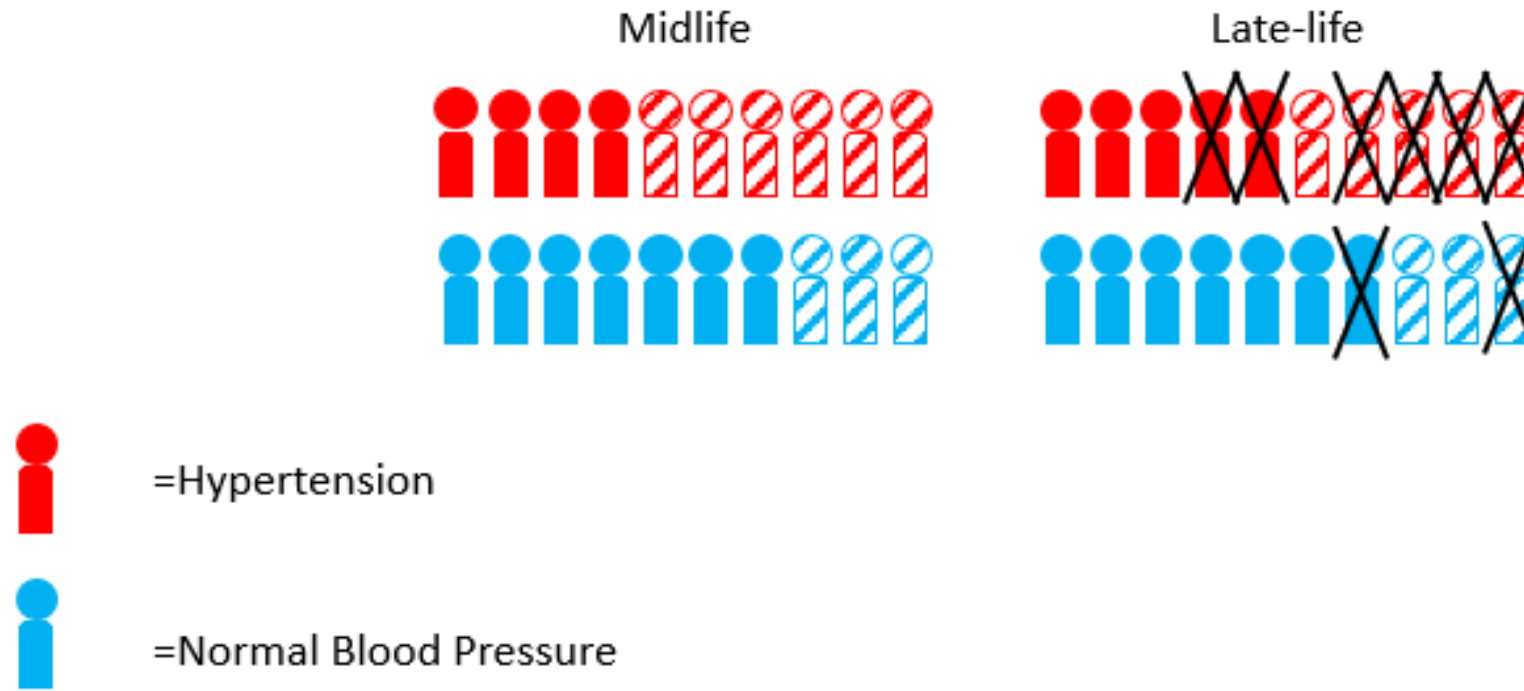
Is it enough to make current studies more “Diverse” ?

Health disparities are systematic differences in health between two populations resulting from **Social Determinants of Health**

- Ask the right questions
- Use the correct methods
- Contextualize the research
 - Example: Education, Bilingualism, Occupation

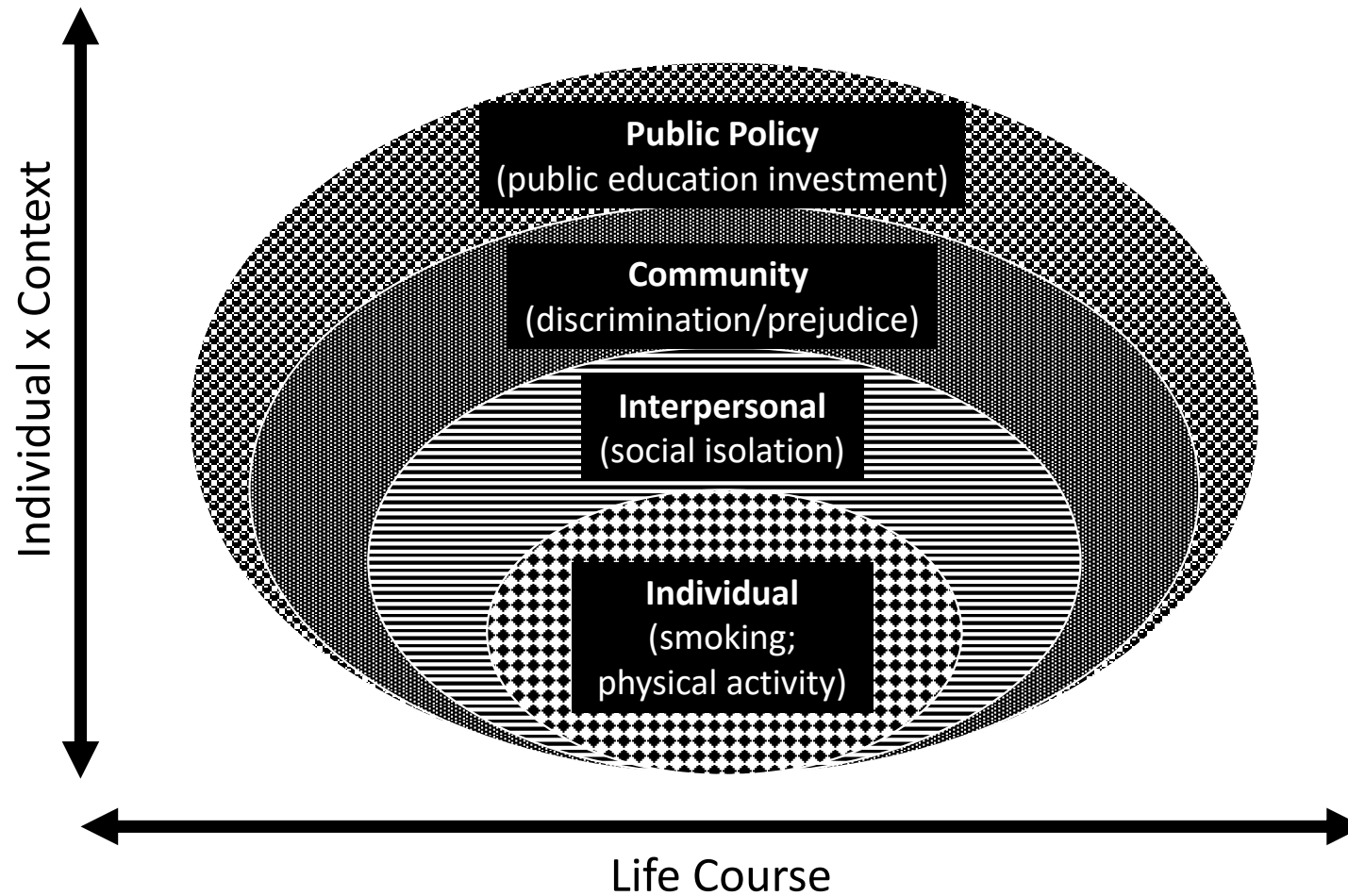


Hypertension and Risk of Dementia: Bias from Differential Survival



How does competing risk of mortality or accelerated aging across different racial groups impact our understanding of risk factors in different populations ?

Cumulative Advantage/Disadvantage



How to move the needle in Epidemiology of ADRD

- Diverse populations nationally and globally
- Contextualized research instruments, cultural relevance
- Balancing depth and breadth: Biomarkers
- Embracing lifecourse approach
- Pooling studies to answer unique questions
- Harmonization
- Methods



THANK YOU !

Park, H., Roubal,, Gennuso, K. P., & Catlin, B. B. (2015). Relative Contributions of a Set of Health Factors to Selected Health Outcomes. *American Journal of Preventive Medicine*, 49(6), 961–969. <https://doi.org/10.1016/j.amepre.2015.07.016>

Gilsanz P, Mayeda ER, Glymour MM, Quesenberry CP, Whitmer RA. Association Between Birth in a High Stroke Mortality State, Race, and Risk of Dementia. *JAMA: Neurology* 2017. Ol: [10.1001/jamaneurol.2017.1553](https://doi.org/10.1001/jamaneurol.2017.1553)

Mayeda ER, M Glymour MM, Quesenberry CP, Whitmer RA. Inequalities in dementia incidence between six racial and ethnic groups over 14 years. *Alzheimer's and Dementia*, 2016.Mar;12(3):216-24. doi: 10.1016/j.jalz.2015.12.007. Epub 2016 Feb 11.

Gilsanz P, Corrada MM, Kawas CH, Mayeda ER, Glymour MM, Quesenberry CP Jr, Lee C, Whitmer RA. Incidence of Dementia After Age 90 in a Multiracial Cohort. *Alzheimers Dement*. 019 Apr;15(4):497-505. doi: 10.1016/j.jalz.2018.12.006. Epub 2019 Feb 20.

Schoeni RF¹, Freedman VA, Langa KM¹ Introduction to a Supplement on Population Level Trends in Dementia: Causes, Disparities, and Projections. *J Gerontol B Psychol Sci Soc Sci*. 2018 Apr 16;73(suppl_1):S1-S9. doi: 10.1093/geronb/gby007

Satizabal CL, Beiser AS, Chouraki V, Chêne G, Dufouil C, Seshadri S. Incidence of Dementia over Three Decades in the Framingham Heart Study. *N Engl J Med*. 2016 Feb 11;374(6):523-32. doi: 10.1056/NEJMoa1504327.PMID: 26863354

Ganguli M, Albanese E, **Seshadri S**, Bennett DA, Lyketsos C, Kukull WA, Skoog I, Hendrie HC. Population Neuroscience: Dementia Epidemiology Serving Precision Medicine and Population Health *Alzheimer Dis Assoc Disord*. 2018 Jan-Mar;32(1):1-9. doi: 10.1097/WAD

Wu YT, Beiser AS, Breteler MMB, Fratiglioni L, Helmer C, Hendrie HC, Honda H, Ikram MA, Langa KM, Lobo A, Matthews FE, Ohara T, Pérès K, Qiu C, **Seshadri S**, Sjölund BM, Skoog I, Brayne C. The changing prevalence and incidence of dementia over time - current evidence. *Nat Rev Neurol*. 2017 Jun;13(6):327-339. doi: 10.1038/nrneurol.2017.63



Disparities in Health, Services, and Interventions for PLWD and Family Caregivers: Evidence and Future Directions

Ladson Hinton MD

Department of Psychiatry & Family Caregiving Institute

University of California, Davis

March 24, 2020

Disclosures

National Institute on Aging

R01 AG064688 (Hinton & Nguyen MPIs)

R24 AG063718 (Park PI)

Additional funding:

National Institute of Mental Health U19 MH113201 (Chen PI)

Archstone Foundation

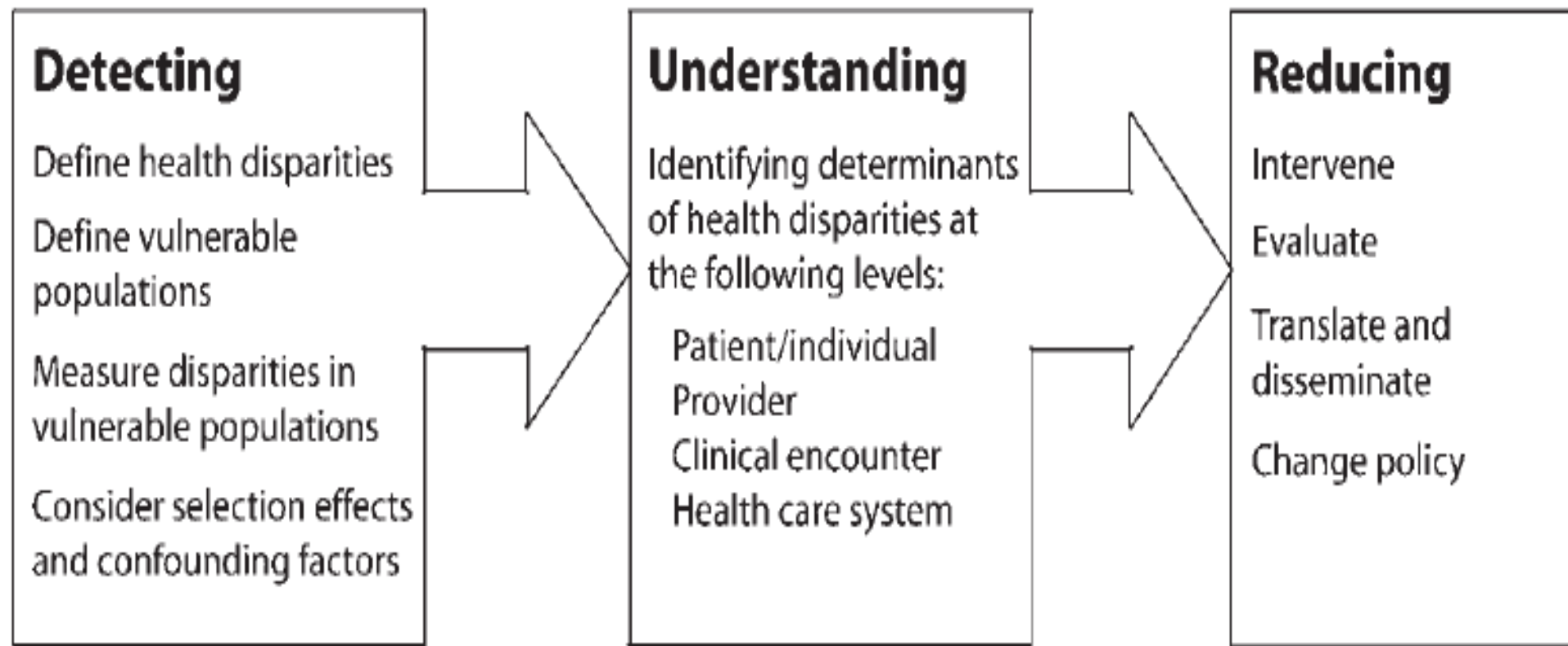
Alzheimer's Association

Key points

- Family caregiving may have greater adverse impacts (e.g., psychological, economic) for certain groups (e.g., racial and ethnic minorities, low SES)
- Growing evidence of disparities in dementia diagnosis, treatment, end-of-life care, particularly for African Americans and Latinx PLWD
- Acute evidence gap for efficacy of non-pharmacological interventions in disparities populations
- Evidence on impacts and care disparities is sparse for many disparities groups and other vulnerable populations

Background

- Ensuring that services, supports and interventions are accessible and effective for all segments of our population is essential for *health equity*
- Racial and ethnic minorities, lower SES, gender and sexual minorities, lower SES and rural populations have historically experienced greater challenges accessing and receiving services.
- Detecting, understanding, and reducing disparities is critical to public health and can enrich science and understanding of mechanisms
- This presentation focuses primarily on racial/ethnic minorities and low SES – for many disparities population there is relatively little evidence.



Note. In our framework, the health disparities research agenda progresses in 3 sequential phases of research. Phase 1 (detecting disparities) informs phase 2 studies (understanding disparities), which in turn informs phase 3 research (interventions to reduce or eliminate disparities).

FIGURE 1—The 3 phases of the disparities research agenda.

Diversity in US older adult population

- **Racial/ethnic minorities: 23%**
- **Live at or near the poverty line: 30%**
- **Identify as LGBTQ: 1 in 20 age 50 and above (2.4 million)**
- **Live in rural areas: 1 in 5**
- **Live alone: 26%**

Sources: US Census Bureau 2016; Kaiser Family Foundation; Choi and Meyer 2016, The Williams Institute

Figure 1

Social Determinants of Health

Economic Stability	Neighborhood and Physical Environment	Education	Food	Community and Social Context	Health Care System
Employment Income Expenses Debt Medical bills Support	Housing Transportation Safety Parks Playgrounds Walkability Zip code / geography	Literacy Language Early childhood education Vocational training Higher education	Hunger Access to healthy options	Social integration Support systems Community engagement Discrimination Stress	Health coverage Provider availability Provider linguistic and cultural competency Quality of care
Health Outcomes Mortality, Morbidity, Life Expectancy, Health Care Expenditures, Health Status, Functional Limitations					

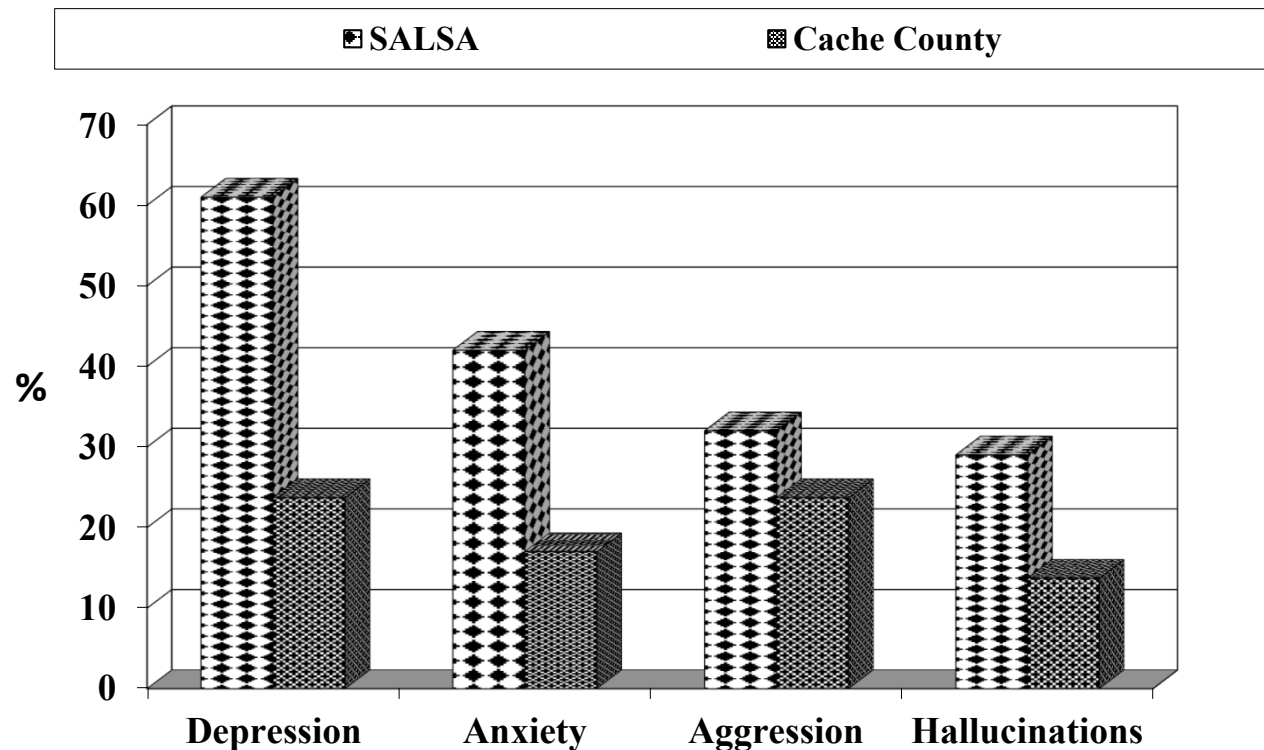
Family caregiving impacts

Disproportionate family caregiving impacts in minority populations

- Provide care that is of higher intensity and longer duration
- Care for PLWD with higher levels of neuropsychiatric symptoms
- Family caregiver psychological distress higher for some groups (Latinx) and lower for others (African Americans)
- Increased out-of-pocket-costs in last 5 years of life as a proportion of wealth (Black, lower educated, single women)

Sources: Friedman et al, Health Affairs 2015; Mayeda et al, Alzheimer's & Dementia, 2016; Sink et al, J Am Geriatric Soc, 2004; Hinton et al, ADRD, 2009; Kelley et al, Ann Intern Med. 2015;

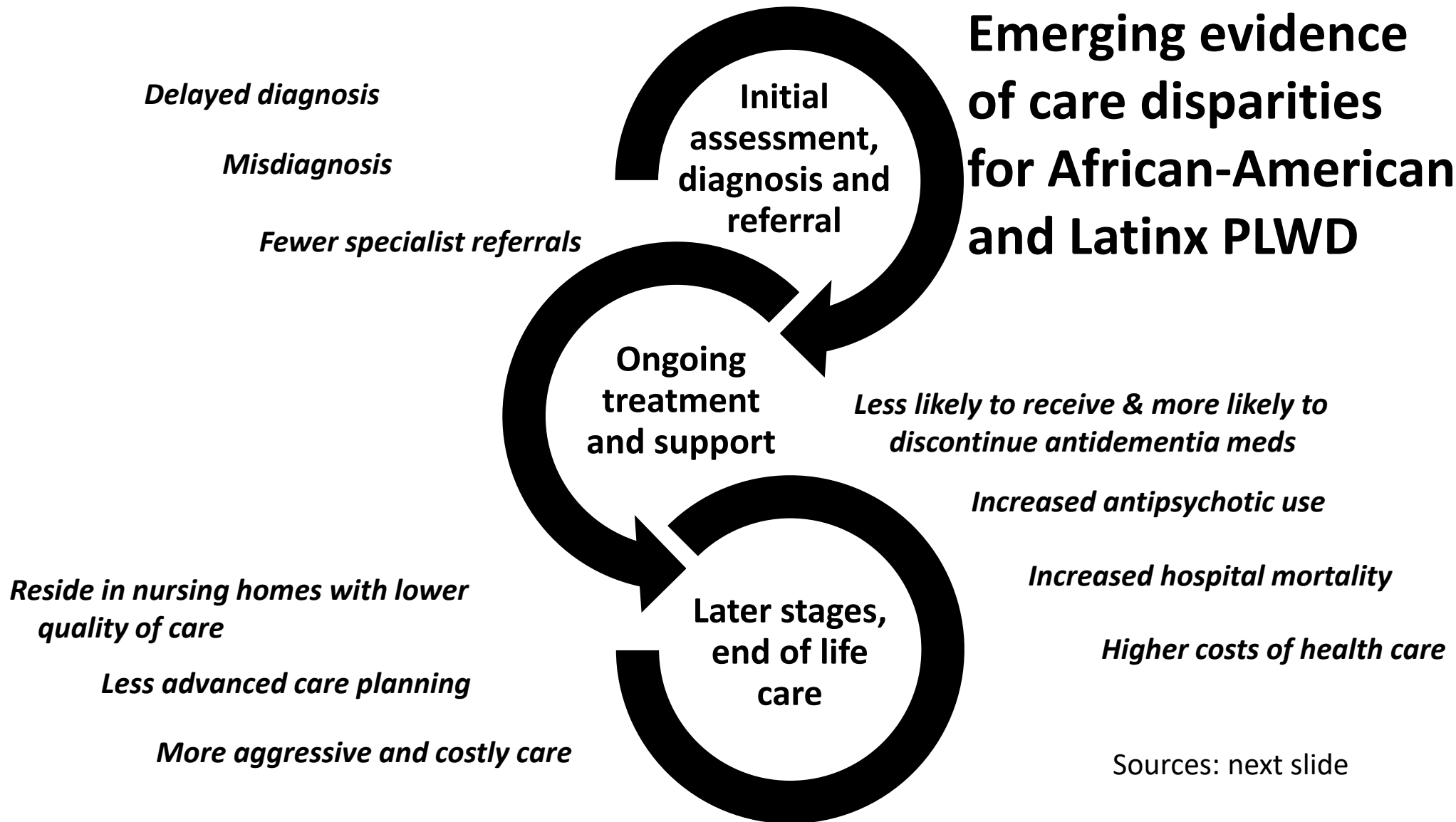
Neuropsychiatric symptoms higher in community-dwelling Latinx (SALSA) with dementia compared with white non-Hispanics (Cache County)



Sources: Hinton et al, Gerontologist 2003; Lyketsos et al, Am J Psy 2000

Dementia care disparities for PLWD

Emerging evidence of care disparities for African-American and Latinx PLWD



Sources: disparities and dementia care

Diagnosis

Amjad et al, JGIM, 2018; Chen et al, Alzheimer's & Dementia: TRCI, 2019; Drabo et al, Alzheimer's & Dementia, 2019; Gianattasio et al, Alzheimer's & Dementia: TRCI, 2019; Livney et al, AJGP, 2011

Ongoing treatment and support

Cooper et al, AJGP, 2010; Gilligan et al, ADAD, 2013; Husaini et al, Psych Ser 2003; Kalkonde et al, Dem Ger Cog Dis 2009; Mehta et al, Neurology, 2005; Ornstein et al, ADAD, 2018; Poon et al, Annals Pharm, 2009; Sherzai et al, J Neuro Neurophysio, 2016; Thorpe et al, JAGS, 2016; Xiong et al, JAGS, 2017; Zuckerman et al, J Geron Psych Soc Sci, 2008

Later stages of care and end-of-life

Harrison et al, JAMA Internal Med, 2016; Mitchell et al, JAMA, 2014; Rivera-Hernandez et al, J Aging Health, 2019

Intervention research

Interventions: current knowledge

- Striking under-representation of disparities populations in clinical trials and interventions (efficacy studies)
- Results often not reported by race and ethnicity – when they do there are often significant effects
- Cultural differences in the experience of dementia and family caregiving exist and may require cultural adaptation of evidence-based interventions (EBI)
- Some evidence that EBI are effective for culturally diverse populations – evidence non-existent for many groups

Race and ethnicity are under-reported in AD/ADRD caregiver support intervention research

- Systematic literature review (1994-2015) of NIH funded studies of dementia caregiver support interventions
- 48 studies identified – 67% included but did not report results by race/ethnicity or gender
- Of studies reporting results by race/ethnicity – 12 (80%) reported statistically significant differences by group
- Many studies not NIH guideline compliant & potentially significant differences by race ethnicity exist

Source: Gilmore-Bykovskyi et al, American Journal of Alzheimer's Disease and Other Dementias, 2018

Pragmatic trials

- Pragmatic trials are likely to be conducted with inadequate evidence based for disparities populations
 - Unique opportunity to advance knowledge if trials are powered to allow for meaningful subgroup analyses
- Implementation is likely to occur in healthcare systems and agencies where healthcare disparities
 - Anticipating and addressing known disparities in the implementation process and monitoring for differential implementation is critical for health equity

Sources: NIA Collaboratory Health Equity Team; Quinones et al, JAGS (submitted)

Summary: critical knowledge gaps

- Evidence on disparities and other vulnerable populations (e.g., other ethnic/racial minority populations, gender/sexual minorities, low SES)
- Disparities mechanisms and reduction where strong evidence exists (e.g., misdiagnosis, antimentia medications) and disparities reduction (e.g., Browne et al, 2013)
- Access and quality of care & support for family caregivers in care systems, including community-based services
- Role of social determinants of health in caregiving impacts and interventions
- Deeper understanding of experience and perspectives of diverse PLWD and family caregivers in critical areas: systems of care, values, technology

Key references

- Babulal GM et al. Perspectives on ethnic and racial disparities in Alzheimer's disease and related dementias: Update and areas of immediate need. *Alzheimer's & Dementia*, 15, 292-312, 2019.
- Brown et al. Collaborative Care Management reduces Disparities in Dementia Care Quality for Caregivers with Less Education. *JAGS*, 243-251, 2013,
- Cooper C, et al. A Systematic Review and Meta-Analysis of Ethnic Differences in Use of Dementia Treatment, Care, and Research. *The American Journal of Geriatric Psychiatry* 18(3):193–203, 2010.
- Kilbourne et al., Advancing Health Disparities Research Within the Healthcare System. *AJPH*, 96(12): 2113-21, 2006.
- Lines LM, Wiener JM. Racial and Ethnic Differences in Alzheimer's Disease: A literature Review. ASPE, 2014. <https://aspe.hhs.gov/report/racial-and-ethnic-disparities-alzheimers-disease-literature-review> .
- National Academies of Sciences, Engineering, and Medicine. Families Caring for an Aging America, 2016.



Economic Impact of Alzheimer's Disease and Related Dementias for Individuals, Care Partners and Society

Julie Zissimopoulos, PhD
University of Southern California
March 24-25, 2020

Disclosures

Funding from the National Institute on Aging through grants:

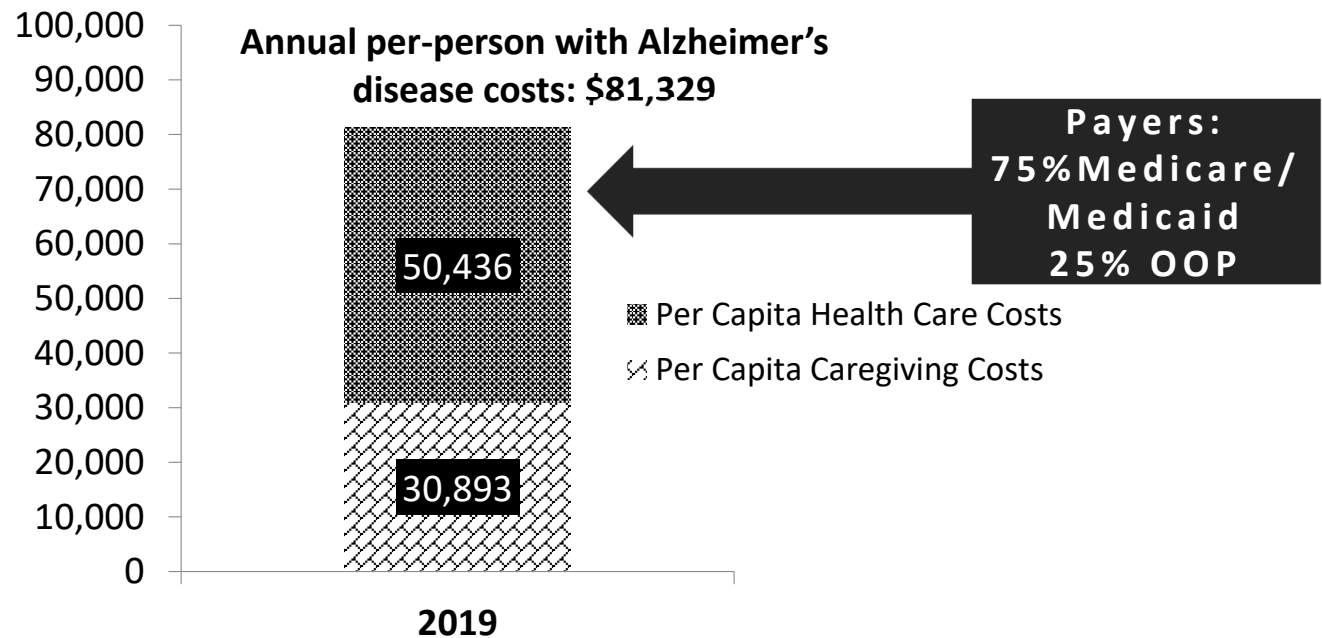
R01AG055401 (PI Zissimopoulos)

P30AG043073 (PI Zissimopoulos, Goldman)

P30AG024968 (PI Goldman)

Annual Health Care and Value of Unpaid Caregiving Costs Are High for Person Living with Dementia

- Estimates across studies vary but not widely;
- Choice of method for valuing care partner's time impacts magnitude

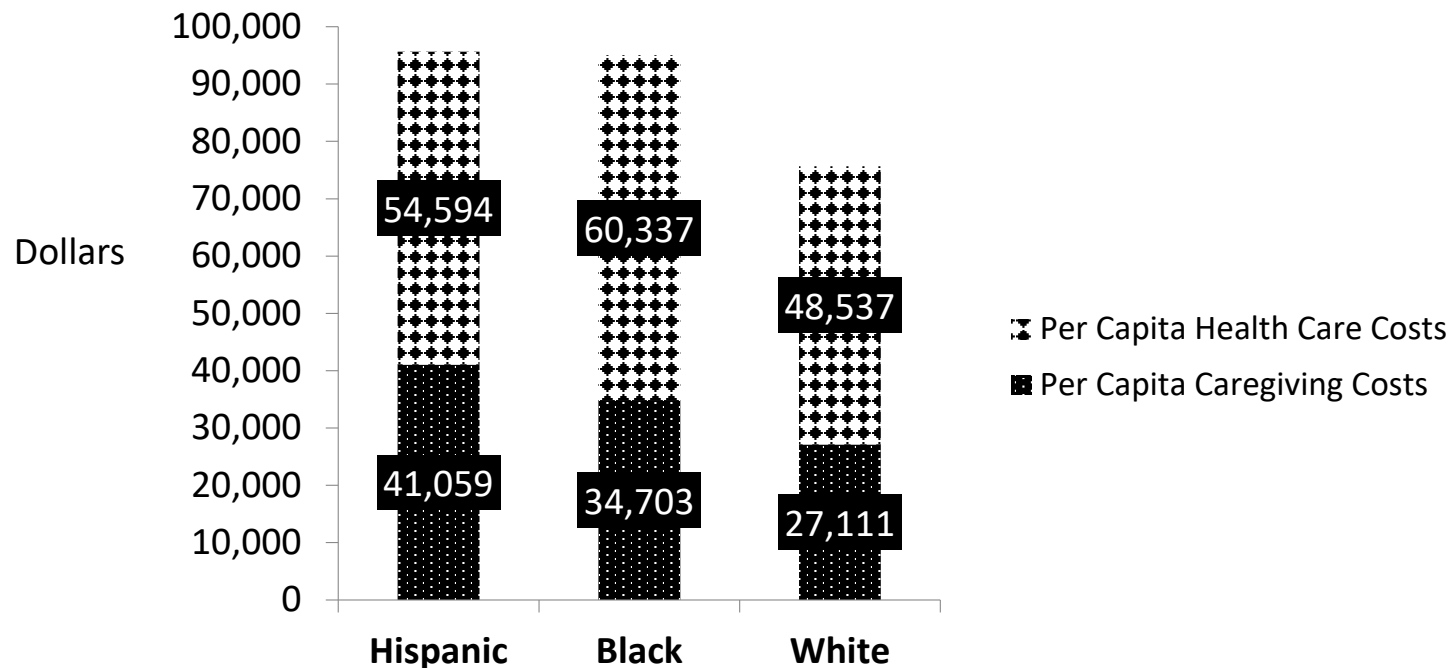


Per Capita Health Care Cost and Dollar Value of Unpaid Family Caregiving

SOURCE: Zissimopoulos et al. 2014

NOTES: Other estimates: (Moore, 2001, informal care \$28k (\$2017); Hurd 2013 total costs \$41k - 56k (\$2013))

Costs Are Higher for Non-White than White PLWD



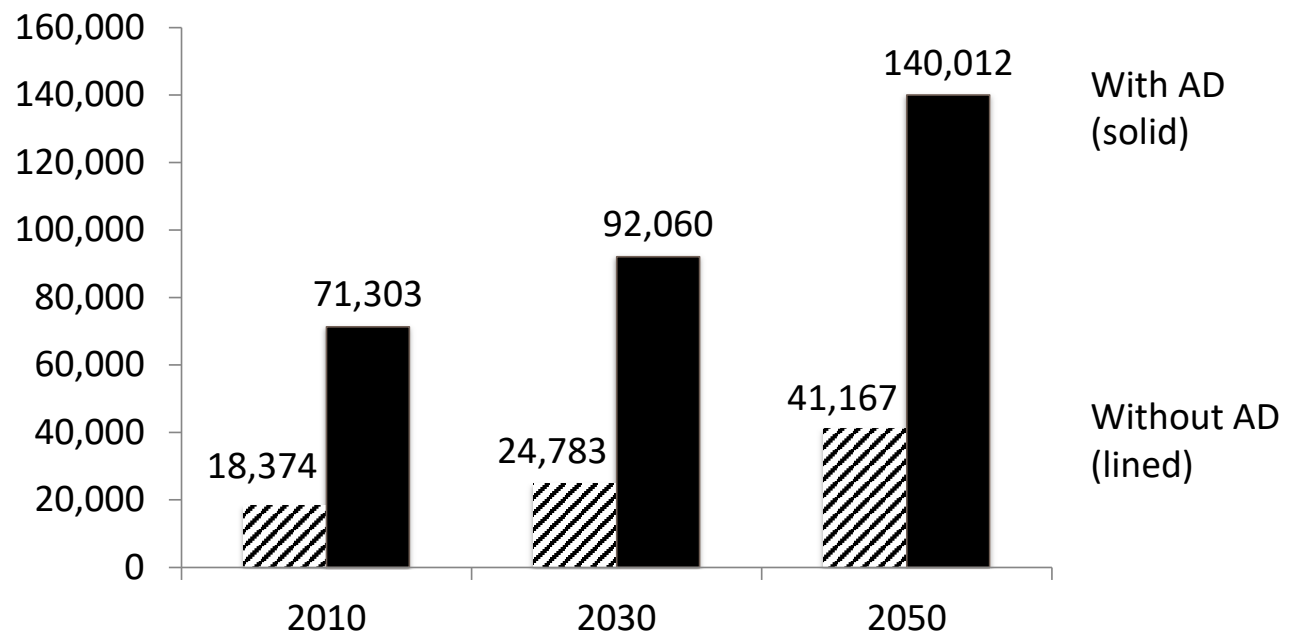
2020 Per Capita Costs of AD by Race/Ethnicity in 2019

SOURCE: Zissimopoulos et al. 2014

Average Annual Costs Are 4 Times Higher for PLWD

'Excess health care cost' of treating PLWD due to more health care use, more hospitalizations and longer stays, more use of post-acute skilled nursing care, home health care (White 2019; Fishman 2019; Lin 2016; Leibson 2015)

Per Capita Annual Medical + Caregiving Costs Of Person Ages 70+ With (solid bars) & Without (lined bars) AD, 2010-2050 (\$2010)

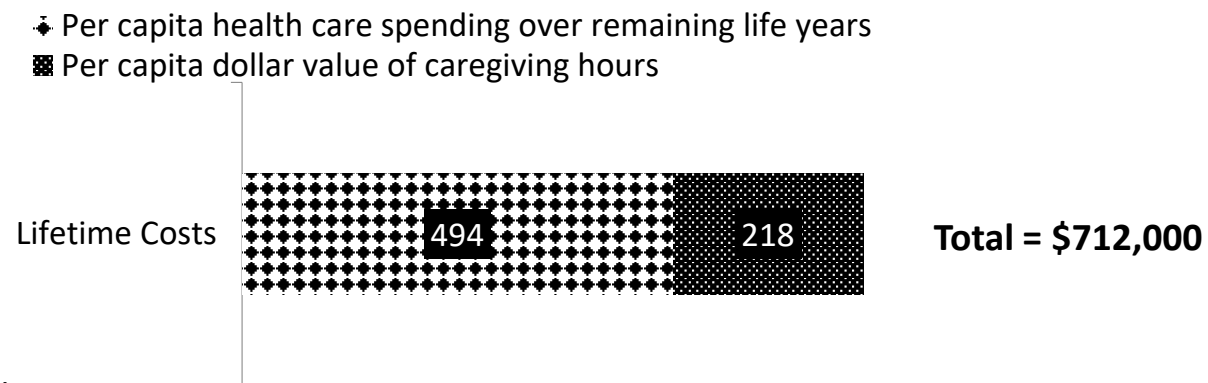


SOURCE: Zissimopoulos et al. 2014

Average Life Time Costs for a 70 Year-Old Who Acquires AD is \$712,000

On average a 70 year old who will acquire Alzheimer's disease before death:

- **15.6 additional life years**
 - **5.8 years with dementia**
 - **2 years of which are in a nursing home**



SOURCE: Zissimopoulos et al. 2014;

NOTES: 70 year old who dies without AD average lifetime costs are \$250,000 (Zissimopoulos, 2014); Hudomiet (2019) quantify lifetime **medical out-of-pocket** spending after age 65 and find persons living with dementia pay \$38,540 more in medical out-of-pocket costs.

Costs of Alzheimer's Disease in 2050 is \$1.6 Trillion

	(\$ Billion)
2010	
Health Care	195
Unpaid Care	126
Total	321
2030	
Health Care	444
Unpaid Care	216
Total	660
2050	
Health Care	1,197
Unpaid Care	361
Total	1,558

*2019 cost of ADRD
Health Care = \$290B
Unpaid Care = \$234B

Total Costs = \$524B
(Alzheimer's Association, 2019)

SOURCES: Table, Zissimopoulos et al. 2014;

Estimates for ADRD from Alzheimer's Association. Alzheimer's Disease Facts and Figures. 2019.

What do we need to know? Improved understanding of heterogeneity in economic impact

Research Opportunities:

- type of cost
- who is impacted
- disease stage
- comorbid conditions
- race/ethnicity/SES
- geo. location
- type of dementia

Costs = medical care + unpaid & paid caregiving/long-term care +?

	Preclinical	Prodromal	Moderate	Severe
PLWD	\$	\$	\$	\$
Care persons	\$	\$	\$	\$
Family	\$	\$	\$	\$
Payers	\$	\$	\$	\$
Society	\$	\$	\$	\$

Intergenerational Impact

ALZHEIMER'S LIFETIME COST STATEMENT

Start Date	End Date	Individuals	Amount Due				
3/1/17	3/1/67	2		\$1,917,150.84			
Applicable Codes							
APPT	DX	DX/MR/PET	RX	CARE	LOST WORK	RESPIRE	NURSING
Qty	Description						Amount
1	Parent, MCI, Alzheimer's, 20 years						\$111,965.54
1	Self Caregiving to Parent, 15 years						\$221,278.70
1	Parent, Nursing Care, 5 years						\$432,448.64
1	Self, MCI, Alzheimer's, 20 years						\$149,689.99
1	Adult Child Caregiving to Self, 15 years						\$469,791.30
1	Self, Nursing Care, 5 years						\$531,976.87
Total						\$1,917,150.84	

SOURCES: Table (modified) and Figure (artificial 'invoice'), editorial, Jonsson et al., Alzheimer's & Dementia (2017).

NOTES: Coe (2018) welfare cost of caregiving 20% higher than opportunity cost measures.

Schaller (2015) review study, costs more than double mild to severe (\$22k - \$52k).

Lin (2013), 23% higher costs for persons with diabetes related hospitalizations and ADRD compared to without ADRD.

Chen (2019), LBD, vascular higher, and FTD lower cost compared to AD, among Medicare beneficiaries in CA; in population of all fee-for-service Medicare Beneficiaries, 30% of diagnosis (dx) of dementia type on medical claims was unspecified, dx changed over time (Drabo 2019); using dx codes alone under-identified blacks and Hispanics with probable dementia (Thunell 2019).

What do we need to know? Drivers of cost differences and impact of policies, programs on distribution of costs

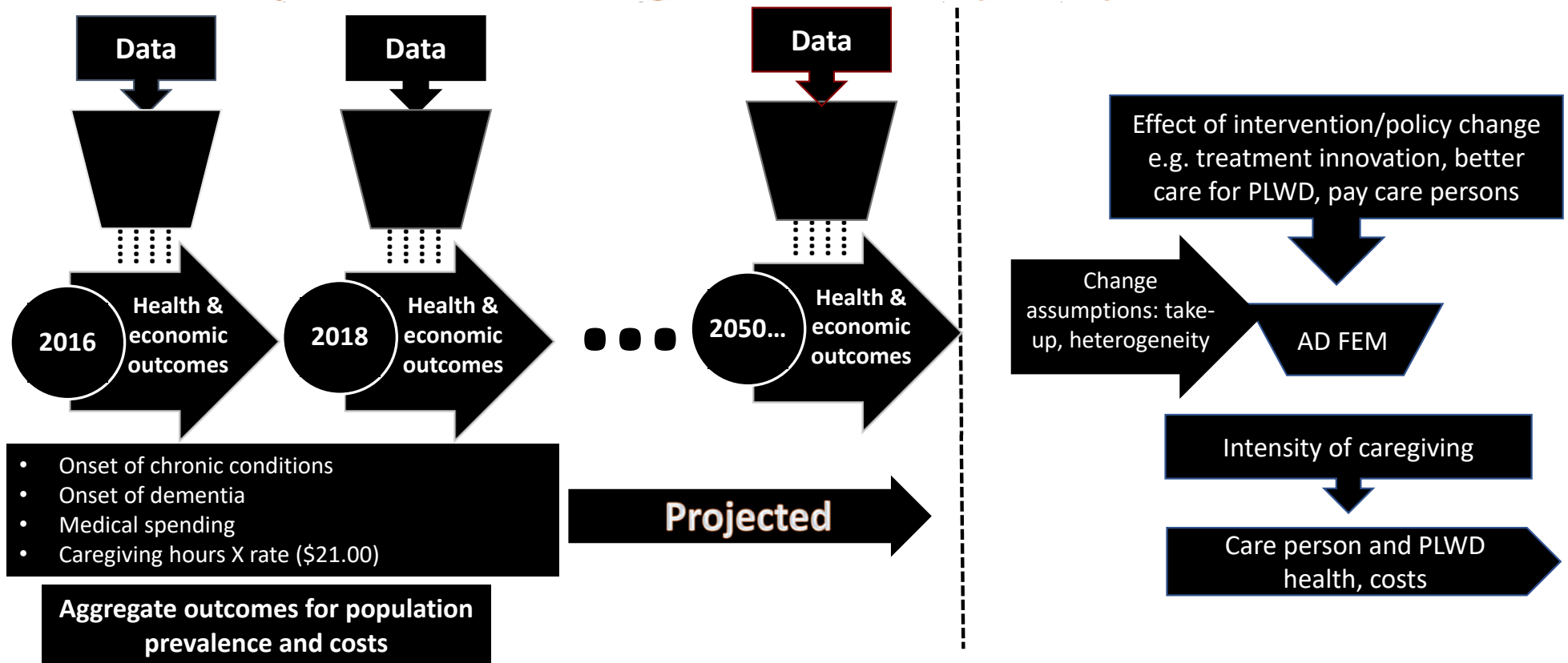
- What care environments are associated with lower costs and why?
- How can high health care expenditures of PLWD be reduced?
- Will Medicare reimbursement for Annual Wellness Visit improve early detection? What will be effect on costs?
- How will paying family care persons impact economic burden, labor force participation and who will bear the costs?
- Will reimbursement incentives to reduce post-acute institutional care decrease Medicare costs and increase costs to families?
- Will better coordinated dementia care reduce hospitalizations, delay nursing home entry and reduce economic impact?

Needs? Longitudinal data linkages combined with rigorous method aid in quantifying variation in costs

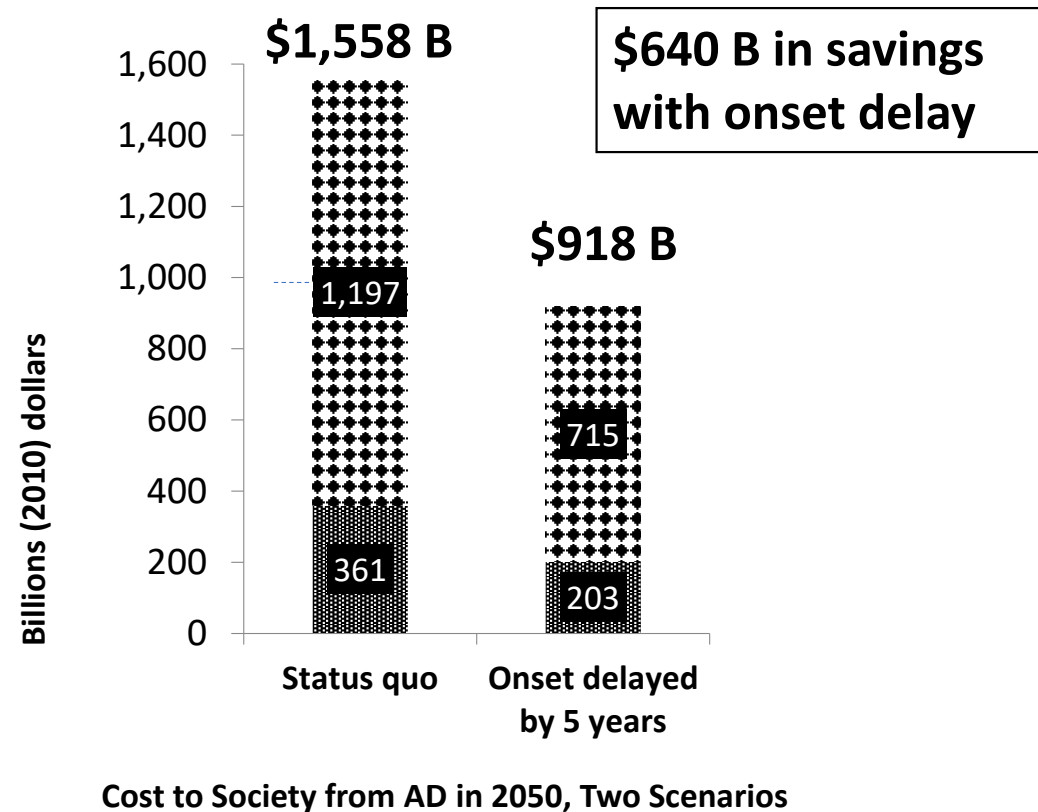
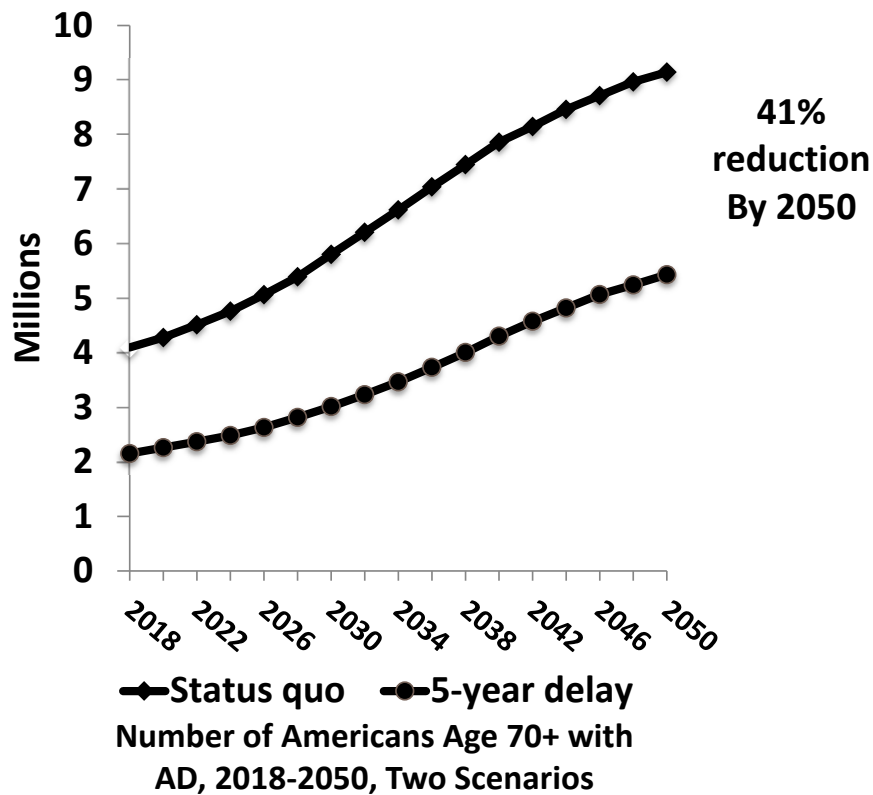
- Timely access to longitudinal data on health and biomarkers, health care providers/system characteristics, and expenditures
- Linkages to surveys with demographic, social, economic and environmental characteristics of PLWD and care persons will provide insight into heterogeneity in costs across persons, types of care, disease stage, dementia types
- Use of rigorous methods for understanding drivers of cost differences across populations

Needs? Models for quantifying costs and evaluating impact of policy changes, interventions

The Future Elderly Model for Understanding Alzheimer's Disease (AD-FEM)



Needs? Models can provide insight into costs and benefits



References

Alzheimer's Association (2019) Alzheimer's Disease Facts and Figures. Chicago, IL

Drabo E., D. Barthold, G. Joyce, P. Ferido, H. Chui, J. Zissimopoulos (2019), Longitudinal Analysis of Dementia Diagnosis and Specialty Care Among Racially Diverse Medicare Beneficiaries, Alzheimer's and Dementia.

Fishman P, Coe NB, White L, et al. (2019) Cost of Dementia in Medicare Managed Care: A Systematic Literature Review, Am J Managed Care. 25:e247-e253.

Hudomiet P. M. Hurd, S. Rohwedder (2019), The Relationship Between Lifetime Out-of-Pocket Medical Expenditures, Dementia and Socioeconomic Status in the U.S., The Journal of the Economics of Ageing.

Hurd MD, Martorell P, Delavande A, Mullen KJ, Langa KM. (2013), Monetary Costs of Dementia in the United States. The New England Journal of Medicine; 368:1326-1334.

Jonsson L. P.J. Lin, A. Khachaturian (2017), Editorial, Alzheimer's and Dementia 13: 201-204.

Leibson CL, Long KH, Ransom JE, et al. (2015), Direct medical costs and source of cost differences across the spectrum of cognitive decline: A population-based study. Alzheimer's & Dementia.

Lin PJ, Fillit HM, Cohen JT, Neumann PJ. (2013) Potentially Avoidable Hospitalizations Among Medicare Beneficiaries with Alzheimer's Disease and Related Disorders. Alzheimer's & Dementia; 9:30-38.

Lin PJ, Zhong Y, Fillit HM, Chen E, Neumann PJ. (2016). Medicare Expenditures of Individuals with Alzheimer's Disease and Related Dementias or Mild Cognitive Impairment before and after Diagnosis. J Am Geriatric Society; 64:1549-1557.

Moore, Michael J., Carolyn W. Zhu, and Elizabeth C. Clipp. (2001), Informal Costs of Dementia Care: Estimates from the National Longitudinal Caregiver Study." *The Journals of Gerontology: Series B* 56, 4: S219-S28.

Schaller S, Mauskopf J, Kriza C, Wahlster P, Kolominsky-Rabas PL. (2015) The Main Cost Drivers in Dementia: A Systematic Review. International Journal of Geriatric Psychiatry; 30:111-129.

Thunell J., P. Ferido, J. Zissimopoulos (2019), "Measuring Alzheimer's Disease and Other Dementias in Diverse Populations Using Medicare Claims Data," Journal of Alzheimer's Disease, 72(1): 29-33.

White L, Fishman P, Basu A, Crane PK, Larson EB, Coe NB. (2019) Medicare Expenditures Attributable to Dementia; 54:773-781.

Zissimopoulos J, Crimmins E, St Clair P. (2014), The Value of Delaying Alzheimer's Disease Onset. Forum for Health Economics & Policy;18:25-39.

Theme 1: Impact of Dementia

This theme includes issues related to heterogeneity and trends in the lived experience of dementia, including the clinical impact and trajectory for people living with dementia and their family caregivers across the range of etiologies; the economic impact of dementia for patients, caregivers, payers, public programs, and society; and the effects of dementia, including the impact of health disparities on diverse populations – for example by sex and gender, socioeconomic status, geography, race and ethnicity, language, education, living arrangements, including people living alone or without caregivers.

Theme 1: Research Opportunity 1

Conduct research to describe the nature, trajectory, and impacts of ADRD on individuals, families, and society with particular attention to the needs, preferences, and strengths of individuals (with and without care partners) living with both common and rare forms of dementia or with complex co-occurring conditions.

Theme 1: Research Opportunity 2

Conduct research to assess the extent to which differences in the nature, trajectory, and impact of ADRD are mediated by heterogeneity among individuals and families with regards to disease etiology, age of onset, disease severity, familial relationship (e.g. spouse/partner, adult child, sibling, in-law), race and ethnicity, socioeconomic status, gender identity, sexual orientation, geography.

Theme 1: Research Opportunity 3

Conduct research to examine the nature, types, trajectory, and impact of implicit bias and stigma against PLWD (with and without care partners) and their care partners on their wellbeing. This includes understanding the lived experience of membership in more than one stigmatized group, i.e., the intersectionality of gender, race, socioeconomic status, rurality, and immigration status--that may heighten vulnerabilities and decrease personal and family agency.

Theme 1: Research Opportunity 4

Conduct research to better describe how social determinants of health (e.g. education, social and economic resources, housing and transportation, healthcare and aging services infrastructure, disability policy, immigration policy, etc.) and attributes of the neighborhood and community in which individuals live, affect the well-being of both people living with dementia (with and without care partners) and care partners.

Theme 1: Research Opportunity 5

Conduct research to determine how risks to wellbeing (e.g. social isolation, marital breakdown, loneliness, financial, legal, psychological vulnerabilities, injuries and self-neglect, etc.) differ between and among care partners based on caregiving circumstances (e.g., living arrangement, competing family and work responsibilities, availability and interpersonal dynamics of family and other helpers, and social and economic resources), as well as the extent to which such differences are mediated by individual and family characteristics along with disease etiology, symptomatology, and age of onset.

Theme 1: Research Opportunity 6

Conduct research to characterize the care settings (e.g. community-based, residential care, other settings) in which PLWD (with and without care partners) receive personal care services, medical, psychiatric, substance use, and recreational services.

Theme 1: Research Opportunity 7

Conduct research to describe how economic and financial burdens affect the lived experiences of persons with dementia (with and without care partners) and their care partners, including choices about diagnosis, treatment and support services, and research participation.

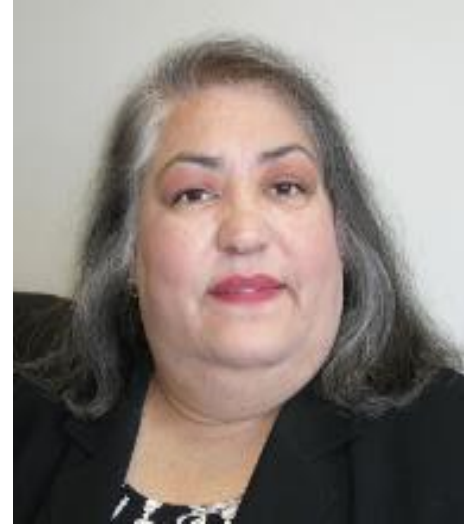
Theme 1: Research Opportunity 8

Conduct research to describe the effects of ADRD on financial status and financial outcomes such as spousal/family impoverishment, reduction or loss of employment opportunities, disruption of employee benefits (e.g. health insurance, accrual of social security benefits and/or private retirement), long-term care insurance, and eligibility for long-term services and supports for PLWD (with and without care partners) and their families and other care partners.

Theme 1: Research Opportunity 9

Test research strategies, practices, or methods to increase recruitment and representation of heterogeneous samples in ADRD research with a focus on methods that increase understanding of the lived experience of groups that have heightened risk, low access to care, and disparate disease burden and stigma.

Theme 1 Panelists



Chanee Fabius, PhD
Cynthia Huling Hummel
Laura Trejo, MSG, MPA
March 24-25, 2020