Theme 1
Impact of Dementia

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

March 24-25, 2020

#DementiaCareSummit
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)
NIA RF1AG052132  (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?

U.S. Population Will Become Increasingly Diverse

- Hispanic Origin
- Asian, Native Hawaiian, and Pacific Islander
- Two or More Races
- Black
- American Indian and Alaska Native
- White

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

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


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)

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

*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 ADRD 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?


**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

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

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.

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
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

Individual x Context

Life Course

Public Policy
(public education investment)

Community
(discrimination/prejudice)

Interpersonal
(social isolation)

Individual
(smoking; physical activity)
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!


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.

Kilbourne et al, AJPH, 2006
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**

<table>
<thead>
<tr>
<th>Economic Stability</th>
<th>Neighborhood and Physical Environment</th>
<th>Education</th>
<th>Food</th>
<th>Community and Social Context</th>
<th>Health Care System</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employment</td>
<td>Housing, Transportation, Safety, Parks, Playgrounds, Walkability, Zip code / geography</td>
<td>Literacy, Language, Early childhood education, Vocational training, Higher education</td>
<td>Hunger, Access to healthy options</td>
<td>Social integration, Support systems, Community engagement, Discrimination, Stress</td>
<td>Health coverage, Provider availability, Provider linguistic and cultural competency, Quality of care</td>
</tr>
<tr>
<td>Income</td>
<td></td>
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<td>Expenses</td>
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<tr>
<td>Debt</td>
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<td></td>
<td></td>
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<tr>
<td>Medical bills</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support</td>
<td></td>
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</tr>
</tbody>
</table>

**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)

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

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

- Initial assessment, diagnosis and referral
- Delayed diagnosis
- Misdiagnosis
- Fewer specialist referrals

Ongoing treatment and support
- Less likely to receive & more likely to discontinue antidementia meds
- Increased antipsychotic use

Later stages, end of life care
- Increased hospital mortality
- Higher costs of health care
- Reside in nursing homes with lower quality of care
  - Less advanced care planning
  - More aggressive and costly care

Sources: next slide
Sources: disparities and dementia care

**Diagnosis**

**Ongoing treatment and support**

**Later stages of care and end-of-life**
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, antidementia 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


• Brown et al. Collaborative Care Management reduces Disparities in Dementia Care Quality for Caregivers with Less Education. JAGS, 243-251, 2013,


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

Per capita health care spending over remaining life years
Per capita dollar value of caregiving hours

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

<table>
<thead>
<tr>
<th></th>
<th>($ Billion)</th>
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<tbody>
<tr>
<td><strong>2010</strong></td>
<td></td>
</tr>
<tr>
<td>Health Care</td>
<td>195</td>
</tr>
<tr>
<td>Unpaid Care</td>
<td>126</td>
</tr>
<tr>
<td>Total</td>
<td>321</td>
</tr>
<tr>
<td><strong>2030</strong></td>
<td></td>
</tr>
<tr>
<td>Health Care</td>
<td>444</td>
</tr>
<tr>
<td>Unpaid Care</td>
<td>216</td>
</tr>
<tr>
<td>Total</td>
<td>660</td>
</tr>
<tr>
<td><strong>2050</strong></td>
<td></td>
</tr>
<tr>
<td>Health Care</td>
<td>1,197</td>
</tr>
<tr>
<td>Unpaid Care</td>
<td>361</td>
</tr>
<tr>
<td>Total</td>
<td>1,558</td>
</tr>
</tbody>
</table>

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

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

**SOURCES:** Table, Zissimopoulos et al. 2014;
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 +?

<table>
<thead>
<tr>
<th></th>
<th>Preclinical</th>
<th>Prodromal</th>
<th>Moderate</th>
<th>Severe</th>
</tr>
</thead>
<tbody>
<tr>
<td>PLWD</td>
<td>$</td>
<td>$</td>
<td>$$$</td>
<td>$$$</td>
</tr>
<tr>
<td>Care persons</td>
<td>$</td>
<td>$</td>
<td>$$$</td>
<td>$$$</td>
</tr>
<tr>
<td>Family</td>
<td>$</td>
<td>$</td>
<td>$</td>
<td>$$$</td>
</tr>
<tr>
<td>Payers</td>
<td>$</td>
<td>$</td>
<td>$</td>
<td>$$$</td>
</tr>
<tr>
<td>Society</td>
<td>$</td>
<td>$</td>
<td>$</td>
<td>$$$</td>
</tr>
</tbody>
</table>

Intergenerational Impact

**ALZHEIMER’S LIFETIME COST STATEMENT**

<table>
<thead>
<tr>
<th></th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent, MCI, Alzheimer’s, 20 years</td>
<td>$171,945.54</td>
</tr>
<tr>
<td>Self-Caring in Parent, 15 years</td>
<td>$221,239.79</td>
</tr>
<tr>
<td>Parent, Nursing Care, 5 years</td>
<td>$221,648.44</td>
</tr>
<tr>
<td>Care, MCI, Alzheimer’s, 20 years</td>
<td>$310,489.99</td>
</tr>
<tr>
<td>Adult Enab/Com하고 SELL, 15 years</td>
<td>$449,793.30</td>
</tr>
<tr>
<td>Self, Nursing Care, 5 years</td>
<td>$331,761.67</td>
</tr>
<tr>
<td>Total</td>
<td>$1,917,150.84</td>
</tr>
</tbody>
</table>

**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)

- Data
  - 2016: Health & economic outcomes
  - 2018: Health & economic outcomes
  - ...: Health & economic outcomes
  - 2050...: Health & economic outcomes

Projected outcomes for population prevalence and costs

- Onset of chronic conditions
- Onset of dementia
- Medical spending
- Caregiving hours X rate ($21.00)

Aggregate outcomes for population prevalence and costs

Effect of intervention/policy change e.g. treatment innovation, better care for PLWD, pay care persons

Change assumptions: take-up, heterogeneity

AD FEM

Intensity of caregiving

Care person and PLWD health, costs
Needs? Models can provide insight into costs and benefits.

- **Status quo** vs. **5-year delay**
- **Number of Americans Age 70+ with AD, 2018-2050, Two Scenarios**

- **41% reduction by 2050**
- **2018-2050, Two Scenarios**

- **Billions (2010) dollars**
- **Cost to Society from AD in 2050, Two Scenarios**

- **Status quo**
  - 1.197 billions
- **Onset delayed by 5 years**
  - 715 billions

- **Savings**
  - 361 billions
  - 203 billions

- **$1,558 B**
- **$918 B**

- **$640 B in savings with onset delay**
References


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.


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