Pursuing Equity in Alzheimer’s and All Other Dementias
A Map Through the Maze Conference 2021

Carl V. Hill, Ph.D., M.P.H.
Chief Equity, Diversity and Inclusion Officer

alzheimer's association®
OUR TIME TODAY

- Landscape of Alzheimer’s and Dementia Research Advances
- Detection, Treatment and Modifiable Risk
- Background Health Disparities and Determinants
- Moving Forward in Pursuit of Health Equity
HALLMARKS OF ALZHEIMER’S DISEASE

Alzheimer’s Pathology

Cortical Atrophy

Neurofibrillary Tangles

Amyloid Plaques

Normal Brain Section

Alzheimer’s Brain Section
2021 Special Report: 
Race, Ethnicity and Alzheimer’s in America

www.alz.org/facts
The Alzheimer’s Association is a global organization working to advance care, support and research across the world.
Alzheimer’s and Related Dementia Research Funding at the NIH

<table>
<thead>
<tr>
<th>Year</th>
<th>Funding (M)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2011</td>
<td>$448M</td>
</tr>
<tr>
<td>2012</td>
<td>$503M</td>
</tr>
<tr>
<td>2013</td>
<td>$504M</td>
</tr>
<tr>
<td>2014</td>
<td>$562M</td>
</tr>
<tr>
<td>2015</td>
<td>$631M</td>
</tr>
<tr>
<td>2016</td>
<td>$991M</td>
</tr>
<tr>
<td>2017</td>
<td>$1.9B</td>
</tr>
<tr>
<td>2018</td>
<td>$2.4B</td>
</tr>
<tr>
<td>2019</td>
<td>$2.8B</td>
</tr>
<tr>
<td>2020</td>
<td>$3.1B</td>
</tr>
<tr>
<td>2021</td>
<td></td>
</tr>
</tbody>
</table>
Exploratory ADRCs: designed to expand and diversify research and education opportunities to new areas of the country, new populations, and new approaches to research.
2021 Alzheimer’s Disease Facts and Figures Report

There are currently **MORE THAN 6 MILLION** Americans aged 65+ living with Alzheimer’s — a number expected to more than double by 2050.

COVID-19 hitting people with Alzheimer’s hard — 42,000 more deaths in 2020 than expected — **16% increase**.

Disease-related costs continue to rise: In 2021: **$355B up $50B** from 2020.
ANNOUNCEMENT SURPRISES THE FIELD

- **March 2019**: Trials halted due to futility analysis conducted on partial data set
- **October 2019**: Announcement expanded data set shows promise
- **December 2019**: Results reported at CTAD
- **March 2020**: Launch of re-dosing studies to provide drug access to trial participants
- **Mid 2020**: Submitting to FDA for regulatory review
- **August 7**: FDA reviewed aducanumab, an anti-amyloid antibody for treatment of dementia and mild cognitive impairment (MCI) due to Alzheimer’s disease. This begins the FDA’s review process under *priority review*.  

[Image: Aducanumab logo]
Cognitively Unimpaired

Mild Cognitive Impairment

Mild Dementia

Moderate Dementia

Severe Dementia

Impairment does not interfere with activities of daily living

Impairment in two or more cognitive functions that interfere with activities of daily living

MCI is a known risk factor for dementia

Everyone who experiences dementia passes through MCI

When you prevent new cases of MCI, you are preventing new cases of dementia
Global Dementia May be Preventable

The Lancet
2017 390, 2673-2734
DOI: (10.1016/S0140-6736(17)31363-6)

FOCUS ON RISK REDUCTION 2017

THE LANCET

The Lancet Commission on dementia

"Effective dementia prevention, intervention, and care could transform the future for society and vastly improve living and dying for individuals with dementia and their families. Acting now on what we already know can make this difference happen."

A Commission By The Lancet

Risk factors for dementia
The Lancet Commission presents a new life course model showing potentially modifiable, and non-modifiable, risk factors for dementia.
A future Alzheimer’s therapy will likely include both lifestyle interventions and medicines.
Gender, Racial and Ethnic Differences in Alzheimer’s Prevalence

• Almost two-thirds of Americans with Alzheimer’s are women.

• Older Black and Hispanic Americans are more likely than older Whites to have Alzheimer’s or other dementias.
Health Disparities Research

Investigation of differences in population-level outcomes that are associated with a broad, complex, and interrelated array of environmental, sociocultural, behavioral, biological factors (*Anderson, 1998). Diagnosis, disease progression, response to treatment, quality of life, health behavior and morality may each be affected by age, education, income, occupation, identity, stress, sex, gender, race, ethnicity, disability status and geography (National Institute on Aging, 2020).
We need to better understand how genes impact Alzheimer’s risk in different peoples.

HISPANICS ARE

1.5 times more likely to develop dementia than non-Hispanic whites.

The ApoE-e4 gene is the strongest known predictor of Alzheimer’s risk for White, European-descended populations.

According to new research reported at #AAIC20, this gene seems to be a less accurate predictor of risk for some Latin American populations.

Additionally, genes that determine Alzheimer’s risk may differ among Hispanics of various origins. This suggests testing positive for ApoE-e4 may not mean the same for Alzheimer’s risk across racial/ethnic groups.
Health Disparities Research Theory (SS)

“... could come to dominate others, it had to originate somewhere, and not in isolated individuals alone, but as a way of life common to the whole groups of man.”

- Max Weber
EARLY LIFE RISK FACTORS

YOUR BMI MAY BE MORE IMPORTANT THAN YOU THINK

According to data presented at AAIC20

Higher body mass index (BMI) between the ages of 20-49 may be associated with higher late-life dementia risk

1.8x higher risk for overweight women

2.5x higher risk for obese women
THE SPRINT-MIND STUDY

First Study (2019) to Demonstrate Reduction of New Cases of Cognitive Impairment
• 9,000+ people, Over age 50, All-cause dementia risk
• Standard vs. Intensive Blood Pressure Intervention
• Intensive treatment 120 systolic vs. 140 systolic
• Dramatic reduction of small vessel disease on MRI

19% REDUCED risk for MCI
17% REDUCED risk for Dementia
15% REDUCED combined risk for MCI and Dementia
U.S. Study to Protect Brain Health through Lifestyle Intervention to Reduce Risk

**Two year multi-center randomized clinical trial**

**Self-Guided and Structured Lifestyle Groups**

**2,000 Participants** at five U.S. sites
A LANDMARK STUDY: TWO LIFESTYLE INTERVENTIONS

Self-Guided Lifestyle Intervention

Structured Lifestyle Intervention

Differ in format, expectations, and accountability

Physical Activity | Nutrition | Cognitive Stimulation | Health Coaching
There are things you can do to reduce your risk of MCI and dementia – especially regarding cardiovascular disease risk factors.

WHY IS THIS IMPORTANT?

Immediate opportunity with life changing impact potential
Health Disparities Research Theory

“To aim for a civilization beyond that made possible by the nexus of the surrounding environment will result in unloosing sickness… Collective activity cannot be encouraged beyond the point set by the condition of the social organism… without undermining health.”

- Emile Durkeim
The role of education in the association between race/ethnicity/nativity, cognitive impairment, and dementia among older adults in the United States

Marc A. Garcia¹, Joseph Saenz², Brian Downer³, and Rebeca Wong⁴
¹Sealy Center on Aging (SCOA), University of Texas Medical Branch, USA. marcagar@utmb.edu.
²Davis School of Gerontology, University of Southern California, USA.
³Division of Rehabilitation Sciences, School of Health Professions, University of Texas Medical Branch, USA.
⁴Department of Preventive Medicine and Community Health, University of Texas Medical Branch, USA.

Abstract

BACKGROUND—Older Black and Hispanic adults are more likely to be cognitively impaired than older White adults. Disadvantages in educational achievement for minority and immigrant populations may contribute to disparities in cognitive impairment.
Social Class and Dementia


Probability of Dementia-Free Survival

Age at Diagnosis, years

High SES
Upward SES- Low education
Downward SES
Low SES
Global Dementia May be Preventable

The Lancet 2017 390, 2673-2734 DOI: (10.1016/S0140-6736(17)31363-6)

FOCUS ON RISK REDUCTION 2020*

*Air Pollution
Traumatic Brain Injury
Excessive Alcohol Use
The appearance of crime among the southern Blacks is a symptom of wrong social conditions – of a stress of life… To be a poor man is hard, but to be a poor… in a land of dollars is the very bottom of hardships”

- W.E.B. DuBois
# The Varying Value of Education

## Heart Disease Death Rates, United States, 1993 - 2001

Age-Standardized, for Blacks and Whites Aged 25-64, per 100,000 (Jemal, 2008)

<table>
<thead>
<tr>
<th>Education</th>
<th>Women</th>
<th>Men</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Blacks</td>
<td>Whites</td>
</tr>
<tr>
<td>All</td>
<td>106.1</td>
<td>37.9</td>
</tr>
<tr>
<td>&lt;12 years</td>
<td>132.9</td>
<td>97.8</td>
</tr>
<tr>
<td>12 years</td>
<td>142.1</td>
<td>50.1</td>
</tr>
<tr>
<td>13-15 years</td>
<td>73</td>
<td>25.1</td>
</tr>
<tr>
<td>16+ years</td>
<td>62.8</td>
<td>16.9</td>
</tr>
<tr>
<td>Low/High Ratio</td>
<td>2.12</td>
<td>5.79</td>
</tr>
</tbody>
</table>
More than one-third of Black Americans, and nearly one-fifth of Hispanic and Asian Americans believe discrimination would be a barrier to receiving Alzheimer’s care

<table>
<thead>
<tr>
<th>Perceived Barriers to Getting Excellent Health Care and Support for Alzheimer’s or Another Dementia Among U.S. Adults</th>
<th>White Americans</th>
<th>Hispanic Americans</th>
<th>Black Americans</th>
<th>Asian Americans</th>
<th>Native Americans</th>
</tr>
</thead>
<tbody>
<tr>
<td>Affordability of care</td>
<td>61%</td>
<td>55%</td>
<td>52%</td>
<td>70%</td>
<td>61%</td>
</tr>
<tr>
<td>Lack of good health care insurance coverage</td>
<td>31%</td>
<td>41%</td>
<td>31%</td>
<td>39%</td>
<td>36%</td>
</tr>
<tr>
<td>Lack of good health care services in my community</td>
<td>20%</td>
<td>24%</td>
<td>27%</td>
<td>27%</td>
<td>24%</td>
</tr>
<tr>
<td>Lack of family and social support to help me</td>
<td>20%</td>
<td>21%</td>
<td>20%</td>
<td>25%</td>
<td>20%</td>
</tr>
<tr>
<td>Being treated differently because of my race, color or ethnicity</td>
<td>1%</td>
<td>18%</td>
<td>36%</td>
<td>19%</td>
<td>12%</td>
</tr>
<tr>
<td>Not being able to communicate easily in English</td>
<td>4%</td>
<td>9%</td>
<td>9%</td>
<td>8%</td>
<td>5%</td>
</tr>
<tr>
<td>Other barriers</td>
<td>2%</td>
<td>1%</td>
<td>1%</td>
<td>1%</td>
<td>2%</td>
</tr>
<tr>
<td>There would be no barriers</td>
<td>21%</td>
<td>17%</td>
<td>20%</td>
<td>12%</td>
<td>14%</td>
</tr>
</tbody>
</table>
Half of Black Americans report experiencing health care discrimination; At least one-third of Native, Asian and Hispanic Americans as well
OTHER FACTORS?

There are things you can do to reduce your risk of MCI and dementia – especially regarding cardiovascular disease risk factors.

Immediate opportunity with life changing impact potential
NIA Health Disparities Research Framework

FUNDAMENTAL FACTORS: Ethnicity, Gender, Age, Race, Disability Status, Identity

**Levels of Analysis**

- Environmental
  - Geographical and Political Factors
    - Structural Bias
    - Immigration/Documentation
    - Discrimination
    - Residential Segregation
    - Urban/Rural
    - Toxins/Exposures

- Sociocultural
  - Cultural Factors
    - Values
      - Prejudice
      - Norms
      - Traditions
      - Religion
      - Collective Responses
  - Social Factors
    - Institutional Racism
    - Family Stress
    - Financial Stress
    - Occupation Stress
    - Residential Stress
    - Social Mobility
    - Social Network

- Behavioral
  - Coping Factors
    - Active Coping
    - Problem Solving
    - Stress Management
    - Cognitive Regulation
    - Emotional Regulation

- Biological
  - Physiological Indicators
    - Cytokine/Inflammatory Response
    - Cardiovascular
    - Sympathetic Nervous System
    - HPA Axis
    - Immune Response
  - Genetic Stability
    - Telomere Attrition
    - Epigenetic Alteration
    - Loss of Proteostasis

- Health Behaviors
  - Smoking
  - Alcohol/Drug Use
  - Nutrition
  - Physical Activity

- Psychological Factors
  - Self-Concepts
  - Stress
  - Bias
  - Loneliness
  - Stigma

- Health Care
  - Access
  - Insurance
  - Quality
  - Literacy
  - Navigators

- Lifecourse Perspective

*Gender and Sex Identity

Adapted from: Anderson (1998); Lazarus & Folkman (1984); Posluszny (1990); Link and Phelan (1995); Corcoran (2000); Williams & Collins (2001); Adler (2000); McEwen (2000); Lopez-Otin (2013)
Health Disparities and Alzheimer’s and All Other Dementias

Priority Populations

Environmental
Sociocultural
Levels of Analysis
Biological
Behavioral

What resources are needed to reduce health disparities in dementia?

< 5% of trial participants are non-White ethnoracial groups

African Americans less likely to be recruited for clinical trials and have higher drop out rates in AD trials

Bioethics
Widely used hypertension drugs less effective in black patients

Researchers are unsure why ACE inhibitors are far less effective for black patients.

By Stephen Feller

NEW YORK, Sept. 15 (UPI) -- One type of drug commonly used to treat hypertension, angiotensin-converting-enzyme, or ACE, inhibitors, was shown in a new study to be associated with significantly worse health outcomes in black patients than white patients, though researchers are unsure why.
RECRUITMENT & RETENTION FOR UNDERREPRESENTED POPULATIONS

• Resources
• Training/Creativity
• Participatory Engagement
• Evaluation Science
• Compliance/Accountabilities
TrialMatch is a free clinical studies matching service designed to provide a customized list of potential study matches to each user.
IN SUMMARY…

• Alzheimer’s Association is a global leader for Alzheimer’s and dementia science

• Exciting time in research
  – New tools for detection and diagnosis
  – Growing diversity of therapies and tools under investigation
  – Need resources and innovation for diverse perspectives and participation

• New research leading to future of therapy that combines drugs and modifiable risk factor interventions
WE ADVOCATE

Alzheimer’s and Related Dementia Research Funding at the NIH

<table>
<thead>
<tr>
<th>Year</th>
<th>Funding (M)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2011</td>
<td>$448M</td>
</tr>
<tr>
<td>2012</td>
<td>$503M</td>
</tr>
<tr>
<td>2013</td>
<td>$504M</td>
</tr>
<tr>
<td>2014</td>
<td>$562M</td>
</tr>
<tr>
<td>2015</td>
<td>$631M</td>
</tr>
<tr>
<td>2016</td>
<td>$991M</td>
</tr>
<tr>
<td>2017</td>
<td>$1.4B</td>
</tr>
<tr>
<td>2018</td>
<td>$1.9B</td>
</tr>
<tr>
<td>2019</td>
<td>$2.8B</td>
</tr>
<tr>
<td>2020</td>
<td>$3.1B</td>
</tr>
<tr>
<td>2021</td>
<td></td>
</tr>
</tbody>
</table>
If we develop a treatment by 2025 that delays the onset of Alzheimer’s by just 5 years, 5.7 million people expected to develop Alzheimer’s in 2050 would not.
Health equity is achieved when every person has the opportunity to attain his or her full health potential and no one is disadvantaged from achieving this potential because of social position or other socially determined circumstances.

Health inequities are reflected in differences in length of life; quality of life; rates of disease, disability, and death; severity of disease; and access to treatment (CDC, 2020).
EPIDEMIOLOGY OF DEMENTIA AND COGNITIVE DECLINE IN DIVERSE POPULATIONS

LISA L. BARNES, PHD
ALLA V. & SOLOMON JESMER PROFESSOR OF GERONTOLOGY AND GERIATRIC MEDICINE

RUSH ALZHEIMER’S DISEASE CENTER
RUSH UNIVERSITY MEDICAL CENTER
While traditional risk factors studied in predominantly White samples provide useful information for understanding disparities, we must incorporate “lived experiences” of diverse participants.
PURSUITING EQUITY IN ALZHEIMER’S and ALL OTHER DEMENTIA

• Increase Diversity in Health System and Health-Related Institutions
• Enhancing Cultural Competence
• Participatory Engagement to Build Trust
• Evaluation Science
• Compliance/Accountabilities
Engagement Partnerships

- Training
- Volunteers
- Community Engagement
- The Longest Day®
- Walk to End Alzheimer’s®
- Conferences and Events
- Advocacy Efforts
- Research
- Concern & Awareness
- Education
- Webinar
- Materials

Local Activation / Other Local Collaborations
Collaborate on health disparities related to Alzheimer’s and other dementias.

June 14-16, 2021 | Virtual Conference
Register today at alz.org/healthdisparities.

Funding for this conference was made possible in part by 1R13 AG071167-01 from National Institute on Aging.
2021 Special Report: Race, Ethnicity and Alzheimer’s in America

www.alz.org/facts
Diversity
- A numerical representation of different types of people.
- Considers differences across many characteristics and beliefs.

Inclusion
- The action or state of including, or being included, within a group.
- Achieving an authentic and empowered participation and a true sense of belonging.

Equity
- Everyone getting what they need to survive or succeed—access to opportunity, resources, and support—based on where we are and where we want to go.
- Different from “equality”, where everyone has the same access to and amount of something, irrespective of need or status.

HALLMARKS OF ALZHEIMER’S DISEASE